

This electronic thesis or dissertation has been downloaded from the King's Research Portal at <https://kclpure.kcl.ac.uk/portal/>



Assistive Technologies used by people with dementia and their carers for the performance of Activities of Daily Living at home and in care homes

Snowden, Suzanne Jane

Awarding institution:
King's College London

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without proper acknowledgement.

END USER LICENCE AGREEMENT



Unless another licence is stated on the immediately following page this work is licensed

under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International

licence. <https://creativecommons.org/licenses/by-nc-nd/4.0/>

You are free to copy, distribute and transmit the work

Under the following conditions:

- Attribution: You must attribute the work in the manner specified by the author (but not in any way that suggests that they endorse you or your use of the work).
- Non Commercial: You may not use this work for commercial purposes.
- No Derivative Works - You may not alter, transform, or build upon this work.

Any of these conditions can be waived if you receive permission from the author. Your fair dealings and other rights are in no way affected by the above.

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Assistive Technologies used by people with dementia and their
carers for the performance of Activities of Daily Living at home and in
care homes

Suzanne Jane Snowden

Thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy

2017

Institute of Gerontology
King's College London

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without proper acknowledgement.

Acknowledgements

My first thanks go of course to my supervisors, Professor Karen Glaser and Professor Anthea Tinker, for their invaluable guidance, insightful comments, and support throughout the research. Thank you both for your dedication to reading the seemingly endless drafts and edits. Thank you for your encouraging words and advice. You are both very inspiring to me.

I extend these thanks to other colleagues within the Institute of Gerontology and Department of Global Health and Social Medicine of King's College London. The advice of staff and fellow PhD students was informative and helpful. Thank you to the Department for the teaching opportunities provided to me. Thank you to Professor Karen Lowton for reading a draft of the thesis. Thank you to past and current members of the Graduate Researchers on Writing group. Your feedback was vital, and I will miss our monthly meetings.

I thank the funders of the research, the Economic and Social Research Council and the care home charity who co-sponsored the project. Thank you to the charity CEO who met with the research team biannually. The charity also acted as gatekeeper to accessing participants from their care homes. Although this was challenging at times, the care homes were a wonderful place to spend a summer of data collection. Thank you to the care home: managers, carers, cleaning staff, and the administrators whom I relied upon to access informal carers. You kept me nourished from the biscuit tin for which I am grateful.

I also thank all the research participants: people with dementia, informal carers, and care home keyworkers, for your essential contribution to the project. Your stories were moving and motivating. I think of you all often.

Thanks to family, extended family, friends, and colleagues for your support and interest throughout the past few years. I thank you for your questions as they always helped to improve my communication to non-academic audiences.

I single out special thanks to my husband, Matt, who has shown patience and love throughout my periods of frustration, self-doubt, and elation. Your sacrifices were innumerable. Thank you for reading the multiple chapter drafts. Thank you for having long conversations with me about writing, concepts, and findings. Thank you for bringing me frequent cups of tea.

Dedications

For Jessie

For Ethel

Abstract

Activities of Daily Living (ADLs) are the basic activities that every adult must perform each day to be considered independent: washing and bathing; grooming and dressing; toileting and continence; and feeding and eating. As people with dementia develop cognitive and physical impairments and functional limitations, their performance of ADLs may be affected. This may necessitate human and technological assistance. The use of Assistive Technologies (ATs) is promoted in policies as enabling people with dementia to live well in their own homes.

The study aim was to investigate informal (family) carers' and formal (paid) carers' perceptions of whether ATs could be used to assist people with dementia to conduct ADLs; and if so, how. This included an exploration of family members' perceptions concerning the contributory role that ATs for ADLs may play in a relocation decision. A mixed-methods study was designed. First, quantitative analyses were conducted on a large, nationally representative dataset. Then, qualitative case studies were created, using care record and interview data.

Key findings of the study demonstrated that carers perceived the use of ATs for ADLs to supplement, but not substitute, human assistance. Device-use was limited by people with dementia when they lived at home, with the exception of mobility-related ATs. Potential use of other ATs was generally unsuccessful; people with dementia lacked insight into their need for human and technological assistance, and could not learn to use new devices. Decisions concerning relocation were triggered by a fall or by the person with dementia becoming lost when outside alone. While mobility-related technologies were perceived to have made life safer for the person with dementia, they had little influence on the decision to enter a care home. Nevertheless, device use was perceived to contribute to quality dementia care in communities and care homes. The key findings have practical implications for policy-makers, social care providers, and AT companies.

Table of Contents

Acknowledgements.....	2
Dedications	3
Abstract.....	4
Table of Contents.....	5
Table of Figures.....	14
Table of Tables	15
Table of Acronyms	16
Glossary.....	17
Chapter 1: Introduction	20
1.1: The problem - gaps in knowledge.....	20
1.2: The response - study aim	21
1.2.1: Research questions	21
1.2.2: Research design	22
1.3: Intended contribution of the study	22
1.4: Thesis structure.....	22
Chapter 2: Dementia - a background.....	27
2.1: An ageing population and a brief summary of the epidemiology of dementia.....	27
2.2: Dementia.....	28
2.2.1: Types of dementia	29
2.3: Diagnosing dementia	30
2.4: Disability performing Activities of Daily Living.....	32
2.5: 'Treatment' of dementia and the provision of social care	33
2.6: Assistive Technologies to help ADL disability	34

2.7: Relevant adult social care policies and social service provision	34
2.7.1: A person-centred framework of social care	35
2.7.2: Social care policies promote technologies to aid living well with dementia	37
2.7.3: Adult social care services	39
2.7.4: Accessing social services: the needs assessment and means test.....	39
2.7.5: Sources of financial assistance for ATs and environmental adaptations	41
2.7.6: Obtaining ATs via social services or private means	42
2.8: The institutionalisation of people with dementia	43
2.9: Chapter 2 summary.....	43
Chapter 3: Dementia and ADL disability	45
3.1: The scoping review - search strategy and critical appraisal	45
3.1.1: Scoping review topics	46
3.1.2: Scoping review approach.....	46
3.1.3: Literature search strategy – three phases	47
3.1.4: The process of appraising relevant literature.....	49
3.1.5: The numerical analysis findings	50
3.1.6: Presentation of the thematic findings throughout Chapters 3, 4, and 5.....	52
3.2: Presentation of reviewed literature for topic 1.....	54
3.3: The disablement process: a pathway from dementia pathology to ADL disability	55
3.4: Decline of ADL performance among people with dementia	60
3.4.1: Bathing and washing.....	61
3.4.2: Grooming and dressing.....	62

3.4.3: Toileting and continence	63
3.4.4: Feeding and eating.....	64
3.4.5: Previous research ignores specific task difficulties within ADLs.....	65
3.5: Moderating factors of the disablement process: carers and technologies	66
3.6: Conceptual overlap between the disablement process model and the person-centred care approach	69
3.7: Human assistance with ADLs: informal carers.....	71
3.8: Human assistance with ADLs: formal carers.....	73
3.8.1: Perceived barriers to formal care services	74
3.9: Chapter 3 summary.....	76
Chapter 4: Assistive Technologies to help people with dementia perform ADLs	77
4.1: Presentation of reviewed literature for topic 2.....	77
4.2: How ATs may assist the performance of ADLs	79
4.3: Assistive Technologies that may be used in daily life	79
4.3.1: Bathing and washing ATs	81
4.3.2: Grooming and dressing ATs	83
4.3.3: Toileting and continence ATs.....	84
4.3.4: Feeding and eating ATs.....	86
4.3.5: Benefits to people with dementia by using ATs for ADL performance	89
4.4: Presentation of reviewed literature for topic 3.....	90
4.5: Assistive Technologies as a substitute for, or supplement to, human carers	91
4.6: Lack of empirical evidence on ATs used by people with dementia living in the community	93
4.6.1: No knowledge concerning how people begin to use ATs.....	95

4.6.2: Lack of evidence outlining where ATs are obtained and the role of formal services.....	97
4.6.3: Gap in knowledge of how use of ATs is maintained	98
4.6.4: Lack of research capturing carers' perceptions of ATs	100
4.7: Ethical considerations for ATs used by people with dementia.....	103
4.8: Understanding dementia for appropriate AT design.....	106
4.9: Chapter 4 summary.....	107
Chapter 5: The transition from community to care home	108
5.1: Presentation of reviewed literature for topic 4.....	109
5.2: Residual disability may explain the need for care relocation.....	110
5.3: Reasons why people with dementia may want to remain at home.....	113
5.4: Triggers for institutionalisation.....	114
5.4.1: Gap in knowledge concerning the role of ATs in institutionalisation triggers and decisions	117
5.5: Decision-making for institutionalisation.....	118
5.5.1: The legal framework	118
5.5.2: The contribution of health professionals and families	119
5.5.3: A decision-making model.....	119
5.6: Presentation of reviewed literature for topic 5.....	122
5.7: Benefits of living in a care home.....	123
5.8: The role of families in care home life	125
5.8.1: Little evidence of perceptions of AT use among care home staff, and staff-family connections.....	126
5.9: Chapter 5 summary.....	127

Chapter 6: Quantitative exploration of low cognition and use of mobility-related ATs	128
6.1: Background and design.....	128
6.2: The ELSA dataset.....	131
6.3: Analytical sample	131
6.4: Outcome variable.....	132
6.5: Independent variables	133
6.6: Analyses	135
6.7: Results.....	135
6.7.1: Distribution of two key variables - mobility-related AT use and cognitive function index	136
6.7.2: Bivariate results	136
6.7.3: Logistic regression model	139
6.8: Strengths of the results.....	142
6.9: Limitations of the analysis	142
6.10: Chapter 6 summary.....	144
Chapter 7: In-depth case studies - method	145
7.1: Study design.....	145
7.2: Ethical approval and risk management	151
7.3: Data security, anonymity and confidentiality.....	153
7.4: Informed consent and Mental Capacity Act (2005) considerations	154
7.4.1: The capacity-to-consent assessment.....	155
7.4.2: Assessment outcome: no capacity-to-consent.....	157
7.4.3: Informed consent procedure for all participants with capacity-to-consent	157
7.5: Stage One of data collection.....	158

7.5.1: Participants	159
7.5.2: Description of care homes	160
7.5.3: Care mapping instrument and other materials	164
7.5.4: Procedure.....	167
7.5.5: Analysis	169
7.6: Stage Two of data collection.....	170
7.6.1: Participants	170
7.6.2: Interview topics and other materials.....	171
7.6.3: Procedure.....	172
7.6.4: Analysis	174
7.7: Changes based on a pilot study	174
7.8: Chapter 7 summary.....	175
Chapter 8: Stage One vignettes	176
8.1: Stage One participants.....	177
8.2: Care record contents	178
8.3: Structure of the vignettes created from care record data	182
8.4: Patterns observed from the vignette data	184
8.4.1: Residents' difficulty performing ADLs.....	184
8.4.2: Assistive Technologies used by and with residents	187
8.4.3: Care home environments	191
8.4.4: Care records an incomplete source of data.....	193
8.5: Selection of Stage One participants for Stage Two.....	194

8.6: Chapter 8 summary.....	196
Chapter 9: Stage Two case studies and the cross-case comparison.....	197
9.1: Stage Two participants.....	197
9.2: Structure of case studies created from Stage One and Stage Two data	199
9.3: Advantages of interview data	201
9.4: Cross-case comparative analysis.....	205
9.5: Theme 1: Cognitive and physical functioning at home.....	206
9.5.1: Performance of ADLs at home	207
9.5.2: Assistance from informal carers	214
9.5.3: Lack of insight impeded the acceptance of ADL assistance.....	214
9.6: Theme 2: Assistive Technologies used at home for ADLs.....	215
9.7: Theme 3: Managing AT use at home	219
9.7.1: People with dementia's negative perceptions prevented AT use	220
9.7.2: Difficulties maintaining appropriate AT use	221
9.7.3: Obtaining ATs.....	222
9.7.4: Negotiating AT use with formal care services	224
9.8: Theme 4: The relocation decision.....	227
9.8.1: The tipping points for institutionalisation	227
9.8.2: Healthcare professionals as catalysts for institutionalisation	229
9.9: Theme 5: Care home life.....	231
9.9.1: Performance of ADLs and associated AT use in care homes	231
9.9.2: Keyworkers perceived that other ATs would not be useful	241

9.9.3: Family visits to the care home and ADL assistance	241
9.10: Chapter 9 summary.....	242
Chapter 10: Discussion.....	244
10.1: Cognitive and physical difficulties impacted on ADL performance	245
10.2: Use of ATs for ADL disability	247
10.2.1: Barriers that prevented use of ATs	247
10.2.2: Factors encouraging AT use	248
10.2.3: Maintaining AT use: a supplement to, not substitute for, human assistance.....	249
10.3: Institutionalisation decisions rarely regarded the presence of ATs	251
10.3.1: Triggers for institutionalisation and the decision-makers	251
10.3.2: Factors considered in decision-making.....	252
10.4: ‘Informal carers’ became ‘family members’ again post-institutionalisation.....	255
10.5: Use of ATs in care homes promoted person-centred care.....	256
10.6: Study strengths	256
10.6.1: Research on ATs moved out of the laboratory	257
10.6.2: Detailed accounts of ADL disability were captured	257
10.6.3: Carers’ perceptions of ATs were identified	258
10.6.4: Study contribution to policy context	258
10.7: Study limitations	259
10.7.1: Care home staff and the Data Protection Act (1998)	260
10.7.2: Personal Consultee procedure.....	262
10.7.3: Reliability of care record data.....	262

10.7.4: Accessible language when discussing ATs	262
10.7.5: Representativeness of participants	263
10.7.6: Case study criticism.....	265
10.8: Recommendations to stakeholders	265
10.8.1: Social care providers and policy-makers	265
10.8.2: Care home providers.....	266
10.8.3: Assistive Technology companies.....	267
10.9: Directions for future research	268
10.10: Chapter 10 summary.....	270
Afterward	272
History.....	272
Subjectivity in analysis	274
References	275
Appendices.....	305
Appendix 1: Mini-Mental State Examination.....	307
Appendix 2: Literature search strategy for the scoping review.....	309
Appendix 3: ELSA analysis.....	317
Appendix 4: Study design - materials and instruments	319
Appendix 5: Stage One vignettes.....	380
Appendix 6: Stage Two case studies	416
Appendix 7: Thematic analysis.....	495

Table of Figures

Figure 1: The disablement process model	58
Figure 2: Additional moderating variables to the disablement process model.....	68
Figure 3: Factors affecting the substitution or supplementation of carers for ATs.....	92
Figure 4: Potential reasons for non-use of ATs.....	100
Figure 5: Accommodations to reduce underlying disability	111
Figure 6: Decision-making model for the institutionalisation of people with dementia.....	120

Table of Tables

Table 1: The pathway from broad topic to research question, resulting from the scoping review	53
Table 2: Distribution of mobility-related AT use among respondents aged 65 years and older.....	136
Table 3: Distribution of total cognitive function index among respondents aged 65 years and older	136
Table 4: Bivariate associations between independent variables and mobility-related AT use	137
Table 5: Multivariate binary logistic regression model of correlates of mobility-related AT use among respondents aged 65 years and older.....	141
Table 6: Details of residents whose care records were mapped in Stage One	178
Table 7: Organisational framework to categorise care record contents	180
Table 8: Assistive Technologies used by participants in the care homes, according to their care record data	189
Table 9: Details of key informants in Stage Two.....	198
Table 10: Assistive Technologies used by people with dementia at home and when resident in the care home according to case study data, and compared to what was indicated only in the care record.....	202
Table 11: Final themes resulting from third level of thematic analysis.....	206

Table of Acronyms

AD.....	Alzheimer's Disease
ADL.....	Activity of Daily Living
ADLs.....	Activities of Daily Living
AMCAT.....	Assessment of Mental Capacity Audit Tool
AT.....	Assistive Technology
ATs.....	Assistive Technologies
BMI.....	Body Mass Index
COPD.....	Chronic Obstructive Pulmonary Disease
CPN.....	Community Psychiatric Nurse
CPR.....	Cardio-Pulmonary Resuscitation
CRB.....	Criminal Records Bureau
df.....	degrees of freedom
DFG.....	Disabled Facilities Grant
DFGs.....	Disabled Facilities Grants
DNR.....	Do Not Resuscitate
DPA.....	Data Protection Act
DVT.....	Deep Vein Thrombosis
ELSA.....	English Longitudinal Study of Ageing
ESRC.....	Economic and Social Research Council
FTD.....	Fronto-Temporal Dementia
GDP.....	Gross Domestic Product
GP.....	General Practitioner
GPs.....	General Practitioners
IADL.....	Instrumental Activity of Daily Living
IADLs.....	Instrumental Activities of Daily Living
LA.....	Local Authority
LAs.....	Local Authorities
LBD.....	Lewy-Body Dementia
LPA.....	Lasting Power of Attorney
MCA.....	Mental Capacity Act
MCI.....	Mild Cognitive Impairment
MMSE.....	Mini-Mental State Examination
MUST.....	Malnutrition Universal Screening Tool
NC.....	Nominated Consultee
NDS.....	National Dementia Strategy
OT.....	Occupational Therapist
OTs.....	Occupational Therapists
PC.....	Personal Consultee
PCs.....	Personal Consultees
RemPod.....	Reminiscence Pod
SALT.....	Speech and Language Therapist
SCREC.....	Social Care Research Ethics Committee
STRATIFY.....	St. Thomas Risk Assessment Tool In Falling Elderly Inpatients
TIA.....	Transient Ischaemic Attacks
UK.....	United Kingdom
USA.....	United States of America
UTIs.....	Urinary-Tract Infections
VaD.....	Vascular Dementia

Glossary

Assistive Technology (AT) and Assistive Technologies (ATs): ‘any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed’ (Cowan and Turner-Smith, 1999, World Health Organization, 2004).

Activity of Daily Living (ADL) and Activities of Daily Living (ADLs): basic and routine tasks necessary for self-care and to be performed at least once every day, for example: washing, bathing and other hygiene-related activities; grooming; dressing; toileting and associated continence management; feeding, eating, and drinking (Katz, 1983).

Care home: an umbrella term referring to a residential or nursing facility which provides accommodation and care services such as domestic, social care, and health or medical care.

Care plan or care record: a document held at field-site care homes, which chronicles the types and frequency of the care services that a resident requires.

Carer (formal and informal): an individual who provides support and assistance to another. A formal carer is contracted and employed to provide assistance; an informal carer is unpaid and typically a family member, friend, or neighbour of the person who requires assistance.

Caring dyad: the person with dementia and their family member, or the care-recipient and their informal carer.

Community setting: the person living in their home in a non-care home location. This includes privately-owned or rented accommodation, and sheltered housing schemes.

Co-morbidities: two or more pathologies, diseases, or long-term conditions, occurring in the individual at the same time.

Dementia: a syndrome resulting from damaged and expired brain tissue, which affects its structure and functioning.

Disability: difficulty performing, and therefore possibly the inability to complete, one or more ADLs.

Disablement process model: a conceptual framework initially developed by Nagi (1965, 1991) and modified by Verbrugge and Jette (1994), used in this thesis to demonstrate the pathway from dementia pathology to ADL disability.

Disorientation: confusion in relation to time, date, place, or person. The opposite state to orientation.

Environment: physical, architectural, socio-cultural, financial, and attitudinal factors external to the individual. These can have an enabling or disabling effect on ADL performance.

Functional limitations (cognitive and physical): the inability to perform appropriate actions at whole body level as a result of impairments. An example of a cognitive functional limitation is difficulty recalling a word list; an example of a physical functional limitation is reduced grip strength.

Healthcare: any care that is considered clinical or medical in nature and that promotes, maintains, or monitors health.

Impairment (cognitive and physical): abnormalities in bodily systems at cellular level as a result of pathology, such as dementia. An example of a cognitive impairment is hindered verbal fluency; an example of a physical impairment is muscle weakness.

Incontinence: relates to both the inability to control bodily functions resulting in involuntary leakage of urine or faeces, and evacuation in an incorrect location.

Independence: exercising choice concerning what happens to the self regardless of ill-health and disability, including control over the extent to which external assistance with ADLs is received.

Institutionalisation: both the process of transitioning to a placement in a care home, and the act of residing in such a location.

Instrumental Activity of Daily Living (IADL) and Instrumental Activities of Daily Living (IADLs): everyday tasks including: housekeeping, shopping, managing finances and paying bills, using the

telephone, and negotiating transport (Lawton and Brody, 1969). They require greater cognitive, physical, and social functioning than ADLs.

Keyworker: formal carer employed at a care home allocated specific responsibilities in relation to a particular resident, such as monitoring his or her care.

Occupational Therapist: a professional trained to assess and treat individuals with respect to ADL performance through rehabilitation, exercise, AT use, or the installation of environmental modifications.

Pathology: used in the disablement process model to refer to a disease state or otherwise diagnosed medical condition, such as dementia, leading to cognitive or physical impairments.

Social care: human or technological assistance with ADL performance; considered a non-medical issue even if the difficulty is partly determined by a health condition.

Speech and Language Therapist: a professional trained to assess and treat difficulties in speech, language, swallowing, eating, and drinking.

Symptom: a sign of disorder or disease which signifies a change from normal function.

Telecare: a type of technology related to enhancing safety; they may connect directly to a call centre when the user is in need. These types of technologies were not under investigation in this thesis.

Well-being: a state of physical, psychological, and social wellness.

Chapter 1: Introduction

In this chapter, a brief introduction to this research project is given. First, the main problem is presented: there are multiple gaps in knowledge concerning the use of technological devices by and with people clinically diagnosed with dementia when performing everyday tasks. Specifically, the focus is on the performance of the basic Activities of Daily Living (ADLs): washing and bathing; dressing and grooming; toileting and continence; and feeding and eating. Human and technological assistance to support people with dementia to perform ADLs are well-known coping strategies. Examples of technological devices for ADLs include, but are not limited to: easy-turn tap heads, long-handled hair brushes, raised and coloured toilet seats, and bowls with tilted bases. However, there are many knowledge gaps concerning the extent to which these Assistive Technologies (ATs) are used by and with people with dementia in community and care home locations.

The chapter continues with the response to the problem; the study aim, five research questions, and the design of this study. The bulk of the research used a case study strategy to explore the phenomena in context. That is, difficulty performing ADLs and associated use of ATs by people with dementia in community and care home settings. The intended contribution of the research to wider knowledge is briefly discussed. It is anticipated that, whilst case study designs hinder generalisation to the wider population with dementia, the exploration will contribute to understanding preferences and barriers to use of ATs. The contents of each thesis chapter are then described.

1.1: The problem - gaps in knowledge

Further detailed in Chapter 2, dementia is a syndrome that can significantly impair a person's cognitive and physical functioning, and thus their everyday living (Cahill et al., 2004). A person may live up to 12 years following their dementia diagnosis (Department of Health, 2008). The challenge, and a key policy aim, is to support people with dementia to 'live well' for as long as possible, whether they reside in their own home or in a care home (Department of Health, 2009). A comprehensive scoping review of relevant literature in Chapters 3, 4 and 5 identified five key knowledge gaps concerning how the use of ATs may support people with dementia who display difficulties performing ADLs. The first knowledge gap was that the precise tasks within each Activity of Daily Living (ADL) that may be difficult for people with dementia had to date been unspecified, and the extent to which poor ADL performance was attributed to either internal bodily processes or external-pressure from the environment was unclear (see Chapter 3). Second, it was difficult to determine the ATs that people with dementia and informal carers used for ADLs when living at

home; research on ATs for ADLs largely excluded participants with dementia, and research on people with dementia and ADLs typically ignored their use of ATs (see Chapter 4). Third, there was no knowledge of: how people with dementia began to use ATs for ADLs; where people with dementia or their families obtained the ATs they used and the quality of the relationship that care-recipients and their families had with formal care services when negotiating Assistive Technology (AT) use; how or whether AT use was maintained over time; and carers' perceptions of ATs for ADLs and their preferences and barriers to use (see Chapter 4). Fourth, although research had demonstrated that difficulties with ADLs can be key determinants of institutionalisation for people with dementia, no studies had thus far investigated the contribution of ATs to decisions concerning the relocation of care. That is, whether the use or non-use of ATs triggered or delayed institutionalisation, or was taken into account when making a relocation decision (see Chapter 5). Fifth, there was a lack of knowledge on the ATs used in care homes to support ADL performance, including the perceptions of care home staff towards ATs for ADLs, and whether family and paid carers perceived that ATs used in care homes could contribute to good family-staff relations (see Chapter 5). These gaps in knowledge informed the creation of the study aim, research questions, and objectives.

1.2: The response - study aim

The aim of this research was to investigate informal (family) carers' and formal (paid) carers' perceptions of whether ATs could be used to assist people with dementia to conduct ADLs; and if so, how. This included an exploration of family members' perceptions concerning the contributory role that ATs for ADLs may play in a relocation decision.

1.2.1: Research questions

Five research questions were formulated to address the study aim:

1. What cognitive and physical difficulties did people with dementia have performing ADLs when they resided in the community?
2. What types of ATs did people with dementia and their informal and formal carers use to assist their performance of ADLs while living at home?
3. What were informal carers' preferences, barriers, and facilitators with respect to the use of such ATs by people with dementia when they lived at home?
4. What was the tipping point for the person with dementia to relocate to a care home, and was this decision at all related to ADLs and AT use?

5. How did ATs for ADLs used in care home settings enhance residents' care, and contribute to connections between residents, family members, and care home staff?

1.2.2: Research design

To address these research questions, a mixed-methods research strategy was designed. First, the association between poor cognitive function and the use of mobility-related ATs was explored using data from the English Longitudinal Study of Ageing (ELSA). The results provided a general background about associations between cognition and the use of certain types of devices among a large, nationally-representative sample of people living in England. Second, multiple exploratory case studies captured the particularised daily lives of people with dementia when living at home and in a care home. The case studies were informed by vignettes created from care record data of institutionalised residents with dementia, and from in-depth interviews with residents' informal and formal carers. The case studies outlined: the extent of human and technological assistance given to support ADLs in both the community and in the care home; how informal and formal carers assessed the need for ATs and obtained them; and how informal and formal carers interacted about AT use. A cross-case comparison was conducted. For this, the data from care records and interview transcripts were subject to a thematic analysis. This identified similarities and differences in experiences of ADL disability, and perceptions of the role ATs could have in dementia care.

1.3: Intended contribution of the study

The study findings will contribute to knowledge concerning how ATs for ADLs may best be used to enable people to live well with dementia in different care contexts. The case studies captured the circumstances leading to institutionalisation for people with dementia and, for the first time, determined whether the use of ATs for ADLs contributed to decisions concerning the relocation of care. The diversity of experiences among people with dementia was highlighted. It is not possible, nor desired, to generalise the findings to a wider population given that dementia affects people in different ways and every person has particular needs, experiences, perceptions, and expectations. However, it is anticipated that the findings could contribute to policies and procedures providing more suitable dementia care services, including the provision of appropriate ATs.

1.4: Thesis structure

In this section, brief descriptions of the chapters within this thesis are given. There are ten chapters and an afterward. In Chapter 1, a brief introduction to the study is presented to highlight the main

problem: lack of knowledge of use of ATs for ADLs by and with people with dementia in community and care home settings. The response: the study aim, research questions, and design are given.

In Chapter 2, background information is provided on the key study concepts: a brief summary of the epidemiology of dementia; the diagnosis of this syndrome; description of the ADLs under investigation; and a discussion of the ATs that may be used to assist with ADL performance. Then, social care policies and reports promoting the ideology of living well with dementia are presented. Those that refer to the use of ATs in dementia care are identified. How potential care recipients and their carers can access formal carers and ATs through adult social services is then discussed. Finally, it is acknowledged that many people with dementia may have to relocate from community living to care home residence, and that research on associated links with AT use is needed.

Throughout Chapters 3, 4, and 5, knowledge gaps which resulted from a scoping review of relevant literature on: dementia; ADL disability; human carers and ATs which may assist the performance of ADLs; and the relocation of people with dementia from community to care home, are discussed. The search strategy for identifying and critically appraising papers for the scoping review of literature is presented in the first section of Chapter 3.

In Chapter 3, the focus concerns how and why poor performance of ADLs (termed ADL disability) may occur in people with dementia. The disablement process model (Nagi, 1965, Nagi, 1991) is used to explain how ADL disability occurs and is influenced by both biomedical and social-environmental factors. Chapter 3 continues with the presentation of empirical research investigating how people with dementia may experience ADL disability. Here, the first gap in knowledge is presented: there is a dearth of literature on the task-specific difficulties of people with dementia when performing ADLs. A modified version of the disablement process model is then presented which shows multiple internal and external moderating factors that may delay the experience of disability (Verbrugge and Jette, 1994). The focus of this study is on two of the external moderating factors: human and technological assistance with ADLs. The remainder of Chapter 3 concerns assistance given by humans, termed carers. They may be 'informal' (family members, friends and neighbours) or 'formal' (contracted, paid, and trained care service employees). Barriers that people with dementia and informal carers may have when trying to access formal care services are discussed.

In Chapter 4, the discussion of the external moderating factors to disablement continues with focus on ATs for ADLs. Suitable ATs can: reduce environmental demands, expand the individual's bodily

capacity to perform an action, or reduce the complexity of the task by replacing a step in a sequence. Descriptions are given of ATs that could be used by people with dementia for general daily life, and then the ADLs under investigation. Some consideration is given to whether ATs should be used to substitute for human assistance or merely to supplement carers' work. However, the second knowledge gap identified that to date we know little about the ATs people with dementia and their carers are currently using. The third knowledge gap recognised that there is a dearth of evidence on how people with dementia begin to use ATs, where their devices were obtained, how AT use is maintained, and carers' perceptions of the role technologies have in dementia care. Some ethical concerns and considerations for AT designers are then presented.

In Chapter 5, the scoping review of literature focuses on two locations within which ADL assistance may be received: one's own private dwelling in the community, and in care homes. The discussion concerns the reasons and triggers for institutionalisation; first framed by the introduction of a theoretical model that explains why even those who receive ADL assistance may eventually need to relocate. The reasons why people with dementia would prefer to stay at home rather than live in a care home are then discussed. This is the first of two sections within the chapter which debate staying at home versus residing in a care home. The fourth knowledge gap noted that the role of ATs was usually excluded in research on triggers and decision-making for institutionalisation. A model exploring the multiple factors taken into account by decision-makers in a dementia context is presented to identify where ATs may fit in. The second of the debate sections is then presented, to explore the benefits to people with dementia of living in a care home. Finally, the discussion turns to what is known about ADL performance and assistance during care home life. Here, the fifth knowledge gap identified that there is little empirical evidence on current use of ATs for ADLs in such locations, and no research on the extent to which family members assist with these.

In Chapter 6, the results of a statistical analysis on a nationally-representative dataset are presented. The Wave 5 ELSA dataset (data collected 2010-2011) was analysed to investigate the association between cognitive function and use of mobility-related ATs. Mobility difficulties, and associated use of ATs to accommodate these, are key influencers of poor ADL performance. Analyses also explored relationships between use of these mobility-related ATs and other variables of interest: difficulty performing ADLs, multiple health conditions, and socio-demographic factors of sex, age, and wealth. The results demonstrated that, contrary to previous research, those with the lowest cognitive function were most likely to use mobility-related ATs even when health, socio-demographic, and

disability factors were taken into account. This suggests that people with cognitive impairments are able and active users of mobility-related technological devices to support everyday actions.

The following three chapters detail the qualitative investigation for this thesis. In Chapter 7, description and justification of the research design (case study strategy) and the ethical considerations and procedures for the two stages of data collection are made. In Stage One, data were mapped from the care records of care home residents with a clinical diagnosis of dementia. These data were turned into vignettes which outlined the difficulties participants had when performing ADLs and ATs used to counter these difficulties. The vignettes were also designed to enable the selection of participants for in-depth exploration in Stage Two. For this second stage of data collection, semi-structured interviews were conducted with residents' family members and keyworkers. Interviews with these key informants enabled the collection of detailed experiences and perceptions of AT use and non-use.

In Chapter 8, the details pertaining to Stage One of data collection are presented. First, the Stage One participants, 16 care home residents with a clinical diagnosis of dementia, are introduced. Then, the contents of the care records mapped for relevant data are described. There were a wealth of forms and documents in each care record. Thus, an organisational framework was created to categorise and sub-categorise the data for legible display. The organisational framework enabled the mapped data to be turned into an informative vignette for each participant. The structure of these vignettes is described and four patterns observed in the vignette data are discussed. Care record data alone did not enable a full exploration of the research questions of this study. However, it is noted that the aim of care record mapping was not to be the sole source of case study data, but to enable the selection of particular residents for further in-depth exploration.

In Chapter 9, the full case studies resulting from the combination of care record data with interview data collected in Stage Two are discussed. First, the Stage Two participants are introduced. These were key informants of care home residents with dementia whose care records were mapped. In total, 11 informal carers (family members) and 10 formal carers (keyworkers) relating to 10 residents with dementia were interviewed. The structure of the 10 resulting case studies is then described. The structure followed a time sequence: community life, the relocation experience, and care home life, and also by each ADL under investigation. This enabled comparisons within and between the case studies. Then, some initial observations on comparing the interview data with the care record data are made. That is, the interview method enabled a more complete picture of device use and

non-use, and carers' perceptions of ATs. A cross-case comparison was then conducted; thematic analysis performed on the care record and interview data enabled the identification of similarities and differences in the experiences of ADL disability and AT use. Findings were divided according to five themes, each relating to a research question in this study. Briefly, ATs for ADL performance were rarely used in the community, whereas devices to support immobility were more common. People with dementia lacked insight into their own disability, which impacted their acceptance of any type of ADL assistance. This had an effect on family members' perceptions of the role ATs could have in community-based dementia care. Triggers for institutionalisation were commonly related to immobility and an acute incident such as a fall, or getting lost when outside due to dementia-related disorientation. Relocation decisions often arose from the advice of health professionals. Currently-used or future potential use of ATs was rarely perceived by informal carers as able to delay institutionalisation. In care homes, staff provided opportunities for residents with dementia to perform ADLs for themselves. Yet, it was uncommon for residents to use ATs for ADLs alone. Devices were usually only used for safety reasons and in conjunction with physical help from staff. Families rarely assisted with ADLs with their relatives once they resided in care homes, though some indicated that borrowing ATs from the care homes enhanced their social activities.

In Chapter 10, the key research findings based on the ELSA analysis and the cross-case comparison are considered and placed into the context of previously-published literature. These include: details of cognitive and physical difficulties people with dementia had when performing ADLs; the salient barriers to use of ATs for ADLs; factors that encouraged and facilitated AT use for ADLs in this population; and the main issues for maintaining the use of ATs at home. A key finding concerning the minimal role of ATs in institutionalisation decisions is discussed. The final two key findings consider the contribution of informal carers for ADL assistance to their relatives in care homes, and that the use of ATs in such locations have the potential to promote quality, person-centred dementia care. The chapter continues with the strengths and limitations of the research. Recommendations for social care providers and policy-makers, care home providers, and AT companies are then made. Directions for future research based on the findings and experience of data collection are suggested.

In the Afterword, the researcher reflects on some of her relevant personal and professional history, and how this may have shaped her experience of the PhD. An acknowledgement of subjectivity when performing qualitative analysis, despite striving for objectivity, is made. This reflexivity is important because researchers should always be aware of potential bias during data collection and analysis.

Chapter 2: Dementia - a background

In this chapter, an introductory background to the concepts, topics, and content in this thesis is presented. Links to the following three chapters which present the review of published literature are made. First, a brief context of ageing populations and resulting impact for United Kingdom (UK) expenditure on health and social care is discussed. This is followed by the presentation of the neurodegenerative syndrome known as 'dementia'; what it is and how it is diagnosed using biomarkers and cognitive performance indicators. Importantly, diagnosis is only made when these biomarkers and indicators are also displayed alongside poor performance of ADLs. Since dementia is incurable, the focus of this thesis is on typical coping strategies to manage the performance of ADLs; help from carers and ATs. The chapter continues with a discussion of relevant social policies, which acknowledge that ATs may contribute to living well with dementia. The ways in which people with dementia and their carers may access funded human and technological support for ADLs through adult social services are outlined. In the final chapter section, it is acknowledged that ATs may not completely remove difficulties when performing ADLs; it may eventually become necessary for a person with dementia to relocate to a more supportive environment such as a care home.

2.1: An ageing population and a brief summary of the epidemiology of dementia

The population of England will increase from a projected 54.5 million people in 2015 to 62.1 million people by 2035 (2010 data) (Office for National Statistics, 2015a). Within this growth, the annual numbers of new-born babies will barely alter, whereas the proportion of people aged 65 years or older will increase more than any other age category. In the UK, the proportion of older adults aged 65 years and older will increase from 17.9% of the total population in 2015 to 23.8% in 2035, and the number of adults aged 85 years and older will rise from 1.4 million people in 2010 to 3.5 million by 2035 (Office for National Statistics, 2015a, Office for National Statistics, 2015b). Life expectancy is also increasing, but these extra years of life do not necessarily mean extra years of good health (Office for National Statistics, 2015b). As a person ages, they are more likely to experience co-morbidities, which is the presence of two or more diseases or long-term conditions occurring at the same time in an individual (Dunlop et al., 2002, Newman and Brach, 2001). These co-morbidities are largely treated by the healthcare system, but may also lead to the onset of disabilities which are typically managed by the social care system (Winstein et al., 2012, Dunlop et al., 2002). An ageing population with poor health and disability concerns policy makers, as it necessitates expenditure on health and social care services to meet needs (Winstein et al., 2012).

Dementia is a syndrome associated with ageing and older populations. Although dementia can occur at any age, the older a person becomes the higher their risk of developing it (Stuart-Hamilton, 2006). There are approximately 665,065 people living with dementia in England, and 800,000 throughout the UK (Alzheimer's Society, 2013c). Dementia is prevalent in approximately: 3% of adults aged 65-74 years old; 30% of adults aged 85 years and older; and greater than 40% of people aged 90 years and older (Johns et al., 2009, Lobo et al., 1999, Stuart-Hamilton, 2006). Overall, 61% of all people with dementia in the UK are female (Alzheimer's Research UK, 2015). Projection estimates anticipate an increase to over 1 million people with dementia in the UK by the year 2021 (Alzheimer's Society, 2013c, Alzheimer's Society, 2012). Dementia care is now seen as a major current and future public health issue (Joling et al., 2008, Sloane et al., 2002), as UK expenditure on social care to manage dementia symptoms will rise from 0.6% of Gross Domestic Product (GDP) in 2002 to a projected 0.96% of GDP in 2031 (Comas-Herrera et al., 2011). Currently, dementia is estimated to cost the UK economy £23 billion, although £8 billion of this is the contribution of unpaid family carers (Alzheimer's Society, 2012). This total is anticipated to increase to £27 billion by 2018 (Alzheimer's Society, 2013c). Costs for dementia care are estimated to be greater than the combined costs for cancer, heart disease, and stroke (Department of Health, 2012c). In 2013, dementia was the leading cause of death for females aged 80 years and older, and the second leading cause of deaths for males aged 80 years and older (Office for National Statistics, 2014).

2.2: Dementia

'Dementia' is an overarching term used to describe a variety of symptoms that result from damaged and expired brain tissue (Amella et al., 2008, Johns et al., 2009, Swanson and Carnahan, 2007). Although in normal ageing the brain experiences some cell death, dementia is a pathological state of its functioning (Stuart-Hamilton, 2006). The damage to brain cells causes cognitive and physical impairments which produce symptoms such as: memory loss; difficulties with planning sequences of actions or reasoning; disorientation to date, time, place, and person; visuo-spatial mistakes such as difficulty perceiving between items and incorrectly judging distances; impaired swallowing and other damaged motor skills; affected speech and other language issues; altered personality, mood and emotional reactions; and difficulty managing social skills such as maintaining relationships (Armstrong et al., 2010, Cahill et al., 2007, Cahill et al., 2004, Hagen et al., 2004, Johns et al., 2009, Mihailidis et al., 2004b, Molin et al., 2007, Nugent et al., 2007, Wherton and Monk, 2008). Cognitive and physical symptoms associated with dementia are further addressed in Chapter 3.

2.2.1: Types of dementia

Dementia is an umbrella term which refers to multiple conditions which affect brain structure and functioning, such as Alzheimer's disease (AD), vascular dementia (VaD), Lewy body dementia (LBD) and fronto-temporal dementia (FTD). Each of these types has a specific aetiology, but they share the varied cognitive and physical symptoms described above. This study included participants with any type of dementia, so a brief introduction to the most common types is provided below.

The most common type, AD, presents in 50-66% of all people who have dementia in the UK (Chertkow, 2008, Davies et al., 2009, Hendrie, 1998). It is caused by the abnormal build-up of proteins in the brain, which form clumps called plaques and tangles and affect the functioning of nerve cells (Alexopoulos et al., 2005, Murayama and Saito, 2004). Short-term memory loss and poor judgement are two of the most commonly observed symptoms associated with AD in its early stages (Amella et al., 2008). However, as with all the dementia types, eventually a person may display all of the symptoms that were described earlier.

The second most common type of dementia is VaD, which occurs in 17% of all UK cases of dementia (Davies et al., 2009, Smyer and Qualls, 1999). Vascular dementia refers to brain cell damage caused by pathologies within the vascular system which restrict oxygen supply to the brain. For example, blood vessel ruptures or blocked arteries from blood clots may cause VaD (Stuart-Hamilton, 2006). Therefore, VaD can be common among people who have had a stroke (O'Brien, 2006). As with AD, short-term memory loss is common among people with VaD, although they may initially display more difficulty with reasoning and problem-solving (Libon et al., 2004). Mixed dementia occurs when a person has dementia caused by two or more types, and is present in approximately 10% of all dementia cases in the UK (Davies et al., 2009). The most common mix is AD with VaD.

Lewy body dementia is caused by nerve cell damage as a result of deposits of a protein called Lewy bodies (Perry et al., 1990). It is present in 4% of all diagnosed cases of dementia in the UK (Davies et al., 2009). The protein deposits also cause Parkinson's disease, so the impaired motor movements associated with this condition are also observed in people with LBD (Cahill et al., 2007). Lewy body dementia is associated with more visual and auditory hallucinations, impaired attention, and reduced alertness than usually observed in other dementias (Amella et al., 2008, Cahill et al., 2007).

Fronto-temporal dementia is a type of dementia characterised specifically by damage to the frontal lobe of the brain, and is associated with motor-neurone disease and Pick's disease (Neary and

Snowden, 1996). It presents in only 2% of all people with dementia in the UK (Davies et al., 2009). People with FTD display good memory in the early stages, but may exhibit more aggressive behaviours than in other types of dementia (Cahill et al., 2007).

There are over 100 different types of dementia. However, the others are much more rare and combined contribute to just 2% of all dementia diagnoses in the UK (Davies et al., 2009). They include: dementia related to alcohol abuse, called Korsakoff's syndrome; HIV-related cognitive impairment; and Creutzfeldt-Jakob disease which is caused by an infectious protein (Alzheimer's Society, 2013f, Alzheimer's Society, 2013h). People with dementia will present with any number or combination of symptoms, and demonstrate varying progression of these symptoms over time (Stuart-Hamilton, 2006). This makes designing appropriate care services challenging (De Vreese et al., 2008). A correct diagnosis of dementia type may be crucial for providing targeted care services to aid living well. An early diagnosis is also important in order to enable the person and their families to make future plans. Therefore, correct and early diagnosis is a key policy aim (Dierckx et al., 2007).

2.3: Diagnosing dementia

Diagnosing dementia is difficult, as the only 'true' diagnosis is a post-mortem examination of the brain to directly observe organ damage. In clinical practice, dementia is diagnosed according to the severity of cognitive impairment compared to 'normal' brain function using an assessment tool called the Mini-Mental State Examination (MMSE) (Folstein et al., 1975). This 10-minute, 11-item instrument measures key areas of cognition including: orientation, recall (memory), attention, and comprehension (Cockrell and Folstein, 2002). A copy of the MMSE and its accompanying administration notes for clinicians are provided in Appendix 1. Each item of the instrument is assigned a set amount of points, and the overall score is calculated by summing the points scored. The score ranges from 0 to a maximum of 30 points. A score ≥ 25 points indicates normal function; 21-24 suggests mild cognitive deficiency; a score from 10-20 points implies moderate impairment; and a score ≤ 9 points implies severe deficits in cognition (Kukull et al., 1994). Clinicians may also use physiological tests on the person's blood and urine samples, and brain scans to investigate structural changes in brain tissue and changes in brain activity to determine the presence and type of dementia (Alzheimer's Society, 2014a).

It is pertinent to this study that no matter what the physiological indicators or MMSE score, a diagnosis of dementia is only made if the responder also exhibits difficulties performing ADLs

(Holsinger et al., 2007). Activities of Daily Living are described below in section 2.4. If the person is still able to perform ADLs without difficulty, then a diagnosis of Mild Cognitive Impairment (MCI) is instead made (Albert and Blacker, 2006, Petersen et al., 1999). This is a prodromal phase of dementia occurring when an individual presents with cognitive impairments that are incongruent with normal ageing but do not affect self-care activities. Pertinently, MCI does not always lead to dementia and symptoms can be reversed, whereas dementia symptoms cannot (Alzheimer's Association, 2009, Davies et al., 2009). As such, people with MCI were excluded in this study, as the focus was on people with a clinical diagnosis of any dementia and their ADL performance difficulties.

It is important to acknowledge, however, that MMSE scores may be affected by factors which are unrelated to dementia. For instance, a sensory impairment such as hearing loss can make it difficult for a person to understand the test. Or, some impaired cognition may have been caused by the person's temporary or long-term co-morbidities; for example, urinary-tract infections (UTIs) can cause impermanent delirium (acute confused state) in older adults (Rabins et al., 1982).

Psychological conditions such as depression and anxiety, or mood states such as dysphoria or apathy, may also produce cognitive symptoms akin to dementia (Landes et al., 2005). For example, depression occurs in up to 57% of people with dementia (Greenwald et al., 1989, Liston Jr, 1978, Reifler et al., 1982, Starkstein et al., 2005) and is associated with reduced physical functioning, difficulty performing ADLs, aggression, more inpatient hospital days, and high mortality rates (Kales et al., 1999, Kaup et al., 2007, Lee and Chodosh, 2009, Lyketsos et al., 1999). It is imperative for clinicians to determine the presence of physical or psychological co-morbidities before conducting an MMSE assessment. Thus, a diagnosis of dementia is also only made once other conditions that may cause cognitive impairments have been ruled out (Stuart-Hamilton, 2006). This is especially critical before decisions regarding a person's health and social care needs are made.

The MMSE score is used to categorise a person with dementia according to three broad stages of acuteness of symptoms: mild, moderate or severe (Davies et al., 2009). Dementia is progressive, meaning the symptoms will become more pronounced over time. That is, the person will usually move from mild, to moderate, and then to the severe stage of dementia over their life course. To illustrate using the cognitive function of memory: someone with mild dementia frequently forgets recent events, conversations, or actions and has repetitive speech; when they have moderate dementia they demonstrate memory loss significant enough to hinder their ability to learn new information and only retain well-learned material; eventually they experience severe dementia and have such critical memory loss they remember only fragments of information (Hughes et al., 1982).

Using an example of the ADL of eating, a person with mild dementia may require verbal prompting from carers but can still feed themselves; when they have moderate dementia they require some verbal and physical help to eat; and once they progress to a severe stage of dementia, they are entirely reliant on others to provide total physical assistance (Hughes et al., 1982). There is detailed discussion in Chapter 3 concerning how dementia causes cognitive and physical functional limitations and ultimately leads to impaired performance of ADLs (Mihailidis et al., 2004b, Wherton and Monk, 2008, Robinson and Fisher, 1999, Martin et al., 2007).

2.4: Disability performing Activities of Daily Living

Activities of Daily Living are basic and routine tasks necessary for self-care: washing, bathing and other hygiene-related activities; grooming and dressing; toileting and continence; and feeding and eating (Katz, 1983). Instrumental Activities of Daily Living (IADLs) or 'advanced ADLs' are more complex tasks that require greater cognitive and physical functioning than ADLs. They are also usually associated with social contact with others, such as housekeeping, shopping, managing finances and paying bills, using the telephone, and negotiating transport (Lawton and Brody, 1969). Inability to perform or complete an ADL, or multiple ADLs, may lead to a person being viewed as disabled. The disablement process model (Nagi, 1965, Nagi, 1991, Verbrugge and Jette, 1994) serves as the conceptual framework for this thesis. This model illustrates the process by which pathology such as dementia leads to poor performance of ADLs, but posits that ADL disability is also determined by a person's environment (Nagi, 1965, Nagi, 1991, Verbrugge and Jette, 1994).

Briefly; according to the disablement process model, the cognitive and physical symptoms or impairments of dementia lead to functional limitations. These include: immobility; a reduced ability to plan actions; and inability to recognise errors and correct them (Sarafino, 2006). When a person is required to perform an ADL such as eating, not only do these functional limitations impede performance, but so too do the social and physical environments surrounding the person. For example, the action of eating a bowl of soup is comprised of numerous tasks such as: realising one is hungry (cognitive and physical functional limitations); recognising nearby items as a bowl, spoon, and soup (cognitive functional limitation and environment); understanding how to pick up the spoon (cognitive functional limitation and environment); having enough finger grip and wrist strength to hold the spoon (physical functional limitation); having enough range-of-motion in the shoulder to take the spoon from table to bowl (physical functional limitation); avoiding excess noise to prevent the person becoming distracted or confused (cognitive impairment and environment); and so on.

Therefore, there are multiple opportunities for both bodily and environmental factors to impair a person with dementia's performance when eating soup (Boger et al., 2010, Mihailidis et al., 2000, Roy et al., 2011). The first research question of this study was to explore the cognitive and physical difficulties people with dementia had when performing ADLs in their home environment.

2.5: 'Treatment' of dementia and the provision of social care

There is currently no cure for any type of dementia. Pharmacological interventions, acetylcholinesterase inhibitors and N-methyl-D-aspartate receptor agonists, can slow but not stop the progression of dementia symptoms (Gillette-Guyonnet et al., 2011, Rodriguez, 2005). Furthermore, these drugs can only be given to people with AD (Stuart-Hamilton, 2006, Swanson and Carnahan, 2007). While these medications may have some effect on cognitive symptoms, they do not improve the overall performance of ADLs (Lancioni et al., 2009b). Behavioural interventions to slow symptom progression include: exercise, reality orientation therapy, mind stimulation, and memory drills (Lancioni et al., 2009b, Pope et al., 2003). Again, these have some effect on cognition, but not on overall ADL performance (Lancioni et al., 2009b). This is because, according to the disablement process model, the person's environment can influence ADL performance as much as the person's bodily functions (Nagi, 1965, Nagi, 1991, Verbrugge and Jette, 1994).

Verbrugge and Jette (1994) modified the disablement process model to introduce internal and external supports which moderate the extent to which bodily and environmental factors impede ADL performance. Given that there is no cure for dementia, this thesis focused on the two most common of these external supports to cope with poor ADL performance: human and technological assistance. These two types of help come under social care services. Human assistance may be provided by 'informal' or 'formal' carers. Informal carers are usually the person with dementia's family, friends, or neighbours who are unpaid for their assistance. Formal carers are employed either privately or by the state to provide ADL assistance. However, the definitions can blur, as some family members may be paid for their time caring for their relative under a Direct Payment scheme (Carers UK, 2014), and some formal carers may become friends with the care-recipient. In this thesis, any family member or initial friend actively involved in looking after the person with dementia was referred to as an informal carer even if they subsequently received some monetary payment. Any (at least initial) stranger who was contracted and paid to provide care to the person with dementia was termed a formal carer. The ways in which human carers may verbally and physically assist with ADLs are presented in Chapter 3. Technological assistance with ADLs is introduced below.

2.6: Assistive Technologies to help ADL disability

As indicated in the modified disablement process model (Verbrugge and Jette, 1994), ATs are another type of external support that may assist the cognitive and physical impairments of people with dementia and their subsequent ADL disabilities (Armstrong et al., 2010, Boger et al., 2006, Cahill et al., 2007). An AT is defined as ‘any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed’ (Cowan and Turner-Smith, 1999, World Health Organization, 2004). This definition includes a range of devices from sophisticated, ‘smart’ technologies such as sensors to alert others when a person has fallen or gotten lost, to simple items such as long-handled shoehorns and colourful tap-turners. There are also many dementia-specific ATs to manage cognitive impairments, such as memo-minders to help poor memory, and clocks and room-signs to aid disorientation. As ADL disability is caused by both bodily and environmental processes, so too do ATs work by either expanding the individual’s capacity to perform the activity, or by reducing the demands of their external surroundings (Agree and Freedman, 2003). The devices that may be used for ADLs are described further in Chapter 4. The second research question of this thesis was to explore the ATs actually used by people with dementia, and their informal and formal carers, when living at home.

Indeed, not only can ATs be used by the person alone, but can be used in conjunction with the person’s informal or formal carer. Some discussion of whether ATs can, or should be, used to substitute or supplement the presence of human carers is made in Chapter 4. The use of ATs may help carers by reducing task demand and alleviating time pressure (Mihailidis et al., 2008). This is especially important as people who informally care may have other obligations, such as a job and childcare (Rauhala and Topo, 2003). However, this also leads to a consideration of who ATs really are for; the person with dementia or their carer. This and other ethical considerations of AT use are discussed in Chapter 4. The English social care policy context concerning ATs to be used by and with people with dementia is presented below.

2.7: Relevant adult social care policies and social service provision

Many people with dementia will need human or technological assistance to complete ADLs; this may require involvement from social care services. In this section, first the underlying person-centred framework that shapes the current adult social care system is presented. This is followed by an

outline of the social policies that address the needs of people with dementia and their informal carers. Attention is given to policies that promote AT use. However, they are criticised for focusing on telecare and telehealth devices instead of ATs for ADLs. A discussion of adult social services follows, including the needs assessment and means test people must undertake to access funded formal care services. Other sources of financial assistance specifically designed to access ATs or to adapt the home environment to meet needs are described. Finally, how ATs may be obtained, either from social services or private means, are introduced.

It is noted here that the field-sites for this study were all in England, so the results cannot be generalised to the UK as a whole. Furthermore, the four UK countries each have different policies for the provision of formal care services for ADLs. In Scotland formal care is free; in Wales there is a maximum charge of £50 per week; and in Northern Ireland formal care is free for individuals aged 75 years and older (Age UK, 2013a, Humphries et al., 2010, Knapp and Prince, 2007).

2.7.1: A person-centred framework of social care

Historically, many people with dementia were denied the opportunity to be involved in decisions about their care (Martin and Bartlett, 2003). This was because the dominant perspective of social care followed a biomedical model that viewed people with cognitive impairment as unable to be involved in decision-making (Martin and Bartlett, 2003). This automatically gave health and social care professionals the power to choose the care individuals received (Barbas and Wilde, 2001). Over time, the central ideology, and thus relevant policies and legislative framework, altered to a person-centred perspective (Downs, 2013b, Kitwood, 1997a). The person-centred approach tackles negative societal perceptions about what it means to have dementia (Nettleton, 2013). The perspective advocates for the greater involvement of people with dementia in discussions concerning the care they receive, in order to elicit more sensitive, appropriate, and humane assistance (Innes, 2009). It incorporates both the decision-making of the person with dementia, and carers' abilities to give reactive, individualised care (Downs, 2013a, Kitwood, 1997c, Lymbery, 2010, Martin and Bartlett, 2003, Sabat and Harré, 1992). Person-centred care empowers people with dementia to set the pace for the assistance they receive, which can contribute towards retaining a sense of self, feeling valued, and promoting meaning in their lives (Wey, 2005). The Mental Capacity Act (2005) (MCA) (UK Parliament, 2005) is a person-centred legislative framework which provides guidance to ensure that people with dementia are included in decisions about them, or if they cannot be involved it ensures choices are made in their best interests (Crisp, 1999). The MCA is detailed in Chapter 7.

The ideology underpinning person-centred care is to promote a sense of independence within people with dementia; however, the word 'independence' is ambiguous (Adams and Bartlett, 2003, Vernon and Qureshi, 2000). Historically within gerontological and independent living research, independence was defined as coping, for example with ADLs, without the assistance of others (Vernon and Qureshi, 2000). Many aspects of Western society teach people that they should be self-reliant (Reindal, 1999, Rose, 1989), and should perform ADLs unassisted once adulthood is reached (Secker et al., 2003, Thomas, 2007). Critical scholars felt that this view of independence was favoured by policy-makers and politicians because it would result in cheaper health and social care costs as people strived to do as much for themselves as possible (Oliver, 1990, Vernon and Qureshi, 2000). This meaning of independence infers that dependence is its opposite state; a person who needs to rely on others to help meet their needs, including for ADL performance (Arber and Evandrou, 1993, Wilkin, 1987). A label of dependency can be shameful (Fine and Glendinning, 2005, Gignac and Cott, 1998), and may: negatively affect a person's psychological health; reduce opportunities for employment; or even lead to exclusion from society (Gignac and Cott, 1998). Such meanings of independence and dependence are stigmatising, ageist, and oppressive (Bond and Cabrero, 2007, Thomas, 2007). They are also inaccurate labels, as a 'dependent' person may be able to conduct many other activities for themselves (Williams and Wood, 1988). Furthermore, no human being, by nature a social creature, is able to achieve complete independence from others (Vernon and Qureshi, 2000). All individuals are likely to rely on others for assistance with ADLs or other daily tasks at some point in their lives due to a temporary or permanent condition, such as: injury, illness, or even pregnancy. With these perceptions of independence and dependence, there is potential for every person to be stigmatised (Adams and Bartlett, 2003).

A new meaning of independence elicited from the sociology of disability field (Vernon and Qureshi, 2000). In disability and person-centred care literature, an independent person is one who has control about the way they want to live, regardless of their ill-health or disability (Brisenden, 1989b, Oliver, 1990). What is most important is not that the disabled adult can perform ADLs without help, but that they made their own choices regarding the assistance they do and do not receive (Brisenden, 1989a, Leece and Peace, 2010, Thomas, 2007). With this meaning, independence is achievable and promotes positive well-being, self-esteem, and life purpose (Secker et al., 2003). Further, people with dementia can be empowered to choose the extent of human and technological assistance they receive (Mountain, 2013, Thomas, 2007). However, academics have queried whether older people, including people with dementia, give as much priority to autonomy and independence for ADLs as they do to other life domains such as: preserving physical energy, feeling safe, or feeling

a sense of belonging to their surroundings (Baltes, 1996, Davies et al., 2000). The social care policies framed by the person-centred perspective are introduced below. The discussion includes support for personalised services and that ATs are promoted in governmental policies.

2.7.2: Social care policies promote technologies to aid living well with dementia

People with dementia in England are covered by a plethora of Acts, adult social care policies, recommendations, reports, and guides for best practice in social care services. These range from general policies for older adults such as the 'National Service Framework for Older People' (with subsequent updates) (Department of Health, 2001), and the White Paper 'Our Health, Our Care, Our Say' (Department of Health, 2006), to those specific to dementia: 'Dementia 2012' (Alzheimer's Society, 2012), the 'National Dementia Strategy' (NDS) (Department of Health, 2009), and the Prime Minister's Challenges on Dementia covering 2012-2015 and 2015-2020 (Department of Health, 2015, Department of Health, 2012c, Department of Health, 2012d). These policies and campaigns all commit to key governmental aspirations that every diagnosed person with dementia receives meaningful care and lives well.

'Living well with dementia' includes care services that can be personalised by the person with dementia, or people working with them, to meet their individual needs (Clough et al., 2007). The principles behind this person-centred approach affirm that people with dementia are individuals with unique life histories, that their perspectives are important and valuable, and that their well-being is an important dimension of their lives (National Collaborating Centre for Mental Health, 2006). The theme of personalisation also carries through into policies for technologies; the government recognise that the contribution AT use may have towards the lives of people with dementia is highly individualised, and thus that the provision of technologies should be tailored to the person's wishes and needs (Department of Health, 2013b, Department of Health, 2011).

The increasing need for more research on ATs to address care challenges for people with dementia was outlined in the National Dementia Strategy (NDS) (Department of Health, 2009): the catalytic document for this study. However, ATs in social care service provision have been on the policy agenda for some time. Governmental interest in technology grew from seminal works by Bjørneby et al. (1999) and Marshall et al. (2000) which linked ATs to the person-centred approach to dementia care, at the same time as the approach was becoming the dominant ideology. Subsequent policies and reports relating to adults with disability, older adults, and people with dementia highlighted the new role that ATs could have in a number of key areas such as housing, healthcare, and particularly

social care (Woolham, 2006). For example, the 2015-2020 Prime Minister's Challenge on Dementia (Department of Health, 2015) highlighted that future dementia care should be innovative and incorporate technological solutions, and the White Paper 'Caring for our Future: Reforming Care and Support' (Department of Health, 2012a) recognised the importance of ATs in social care, though this was in reference to the value of telecare and telehealth services.

Indeed, the focus of policies and governmental schemes has notably been on telecare, telehealth, and digital or 'smart' technologies rather than the simpler ATs of focus in this study (see Chapter 4 for descriptions of these types). Examples of national telecare and telehealth governmental programmes and research include: the Preventative Technology Grant programme (The National Archives, 2009); The Whole Systems Demonstrator Project (Steventon and Bardsley, 2012); the '3millionlives campaign' (Department of Health, 2012b); and its successor the Technology Enabled Care Services programme (NHS Commissioning Assembly, 2015). The evidence suggests that to date, these programmes, campaigns, and research projects have evidenced limited effectiveness of telecare (Steventon and Bardsley, 2012). They have been criticised for promoting telecare use with little compelling evidence (Greenhalgh et al., 2012). For example, a randomised controlled trial is currently being conducted to investigate cost-effectiveness of ATs use and time to institutionalisation of AT users compared to a control condition (Leroi et al., 2013). However, the control condition for this study is not the use of no ATs, but having telecare in the form of a pendant alarm; this may somewhat limit findings. Overall, telecare and telehealth devices are likely to have received considerable attention because they are seen by governments as cost-effective ways of reducing social care costs associated with population ageing (Government Office for Science and Foresight, 2016, Woolham, 2006, Wright et al., 2005). This importance placed on cost-effectiveness may somewhat defy the ideology of promoting AT use only in a person-centred manner.

Currently, health and social care services are funded in different ways. For instance, NHS England (healthcare) is funded by the Department of Health, and LAs (social care) are funded by the Department for Communities and Local Government (Bate, 2017). However, this system is now under review with the aim of integrating health and social care in order to improve service provision, commissioning, and funding. This integrated model of care is discussed further in Chapter 10. The current system by which a person with dementia is assessed by adult social care services in order to obtain funded human and technological assistance is described below. This is the system by which the people with dementia and their families who participated in this study would have navigated.

2.7.3: Adult social care services

Local Authorities (LAs) assess a person's social care needs, set the eligibility criteria for funded assistance, and arrange formal care service provision (Comas-Herrera et al., 2006). These social services are funded from central and local taxation and from user-charges (Comas-Herrera et al., 2006). Rehabilitation services assist a person for free up to six weeks following a hospital discharge. These typically combine intermediate (healthcare) and re-ablement (social care) care (Age UK, 2013e). Health and social care via human assistance and ATs are not mutually exclusive options for a potential service-user, and may complement one another.

Formal care service provision for a person with dementia includes: informal carer respite; domiciliary assistance such as housework, shopping, and gardening; home-delivered meals; verbal or physical ADL assistance from formal carers; or the provision of ATs for ADLs from an Occupational Therapist (OT) or other relevant professional (Age UK, 2012a, Raivio et al., 2007). The aims of such services are to help care-recipients to improve or maintain their quality of life, and to provide protection for vulnerable older adults (Age UK, 2012a). Anyone in need of care can apply to social services, but research has demonstrated that people with dementia, compared to cognitively-healthy counterparts of a similar age, are more likely to receive services for ADL assistance than the other services listed above (Hawranik, 1998). Among people who live alone, those with dementia are more likely to use formal care services than cognitively-healthy people (Nourhashémi et al., 2005).

The costs of dementia care are vast, as indicated in section 2.1 (Alzheimer's Society, 2012). Yet, although the government allocated more money to social care in the 2010 Comprehensive Spending Review, older people's social care expenditure was cut by £331 million (4.5%) from 2010/11 to 2011/12 (Age UK, 2012a). People who wish to access funded care from social services are subject to a needs assessment and means test to determine their eligibility. These are described below.

2.7.4: Accessing social services: the needs assessment and means test

Although the system to access funded social care support from adult social services has been frequently changing, the current procedures require first an assessment of the potential care-recipient's needs, and second a means test (UK Parliament, 2014). Every applicant is entitled to a needs assessment (Age UK, 2013a, Social Care Institute for Excellence, 2013). It is carried out by a social services staff member such as a social worker or OT (Age UK, 2012b). The assessment takes into account the person's abilities and skills, support networks, emotional needs, and culture (Age UK, 2013a, UK Parliament, 2014). Informal carers' needs and opinions are also taken into account

(Age UK, 2013a). The potential care-recipient then receives a written care plan detailing the support required to meet their needs (Age UK, 2012b).

The second step is a personal means test to determine the extent to which individuals must make a financial contribution towards the services they may receive (Comas-Herrera et al., 2006). The means test assesses the person's income and savings, including the value of their estate and other assets (Age UK, 2012b, UK Parliament, 2014). At the time the participants in this study had a means test (some years prior to data collection fieldwork) the assets threshold for funded care was set at £23,250. This meant that anyone with income and savings greater than that figure would have had to pay fully for their care, although the amount they paid was not to bring their income below a minimum threshold (Age UK, 2013a, Age UK, 2012b). Anyone with income and savings below £14,250 was entitled to receive fully-funded care (Isden et al., 2013). Even then, people may have been obliged to make some financial contribution provided that they were left with at least £22.30 per week (Isden et al., 2013).

Since the time that the research participants in this study were financially assessed, the Dilnot Report recommended an increase in the upper-limit threshold from £23,250 to £100,000 (Dilnot et al., 2011). The Dilnot Report also suggested that contributions to the cost of care have a maximum limit of £35,000 (Age UK, 2013c, Age UK, 2012a). Although an improvement, the actual government changes fell short of these recommendations (Isden et al., 2013). From April 2020 onwards, people in receipt of social care will be required to make some financial contribution if their income and savings are between £17,500 and £118,000 (Age UK, 2015). They must pay the full amount for their care if they exceed the upper threshold of £118,000 (Age UK, 2015). Care-recipients should pay a maximum contribution of £72,000 in their lifetime, whether they reside in the community or in a care home (Age UK, 2013c, Isden et al., 2013).

The needs assessment and means test results determine the applicant as having overall low, moderate, substantial, or critical needs (Age UK, 2012a). This four-point scale is used by LAs to assess eligibility for receiving state funded care services. In response to demand from ageing populations and a reduction in their budgets, LAs have had to raise the eligibility threshold for funded care services only to those with critical needs (Comas-Herrera et al., 2006, Humphries et al., 2010). In 2009-2010, 50% of councils provided support to people with moderate to critical needs; this reduced to 15% of councils in 2011 (Care Quality Commission, 2011). By 2012, around 80% of councils funded care only to people with substantial needs or greater, and 3% of councils only

provided assistance to those with critical needs (Age UK, 2012a). This indicates a postcode lottery for care, as the likelihood of receiving state funding depends upon the person's location (Age UK, 2012a). The Dilnot Report recommended that this postcode lottery be eradicated with a nationwide eligibility threshold, which was in place by April 2015 (Isden et al., 2013, Department of Health, 2013a). The people with dementia in this study resided in different LAs, and although their informal carers were not asked to detail the outcome of their means test, they were asked to indicate whether any ATs used were funded or provided by adult social services. There are other Parliamentary Acts by which people with dementia may apply for ATs and environmental adaptations; these are described below.

2.7.5: Sources of financial assistance for ATs and environmental adaptations

Under the Housing Grants, Construction and Regeneration Act (1996) (UK Parliament, 1996), people with dementia are eligible to apply for Disabled Facilities Grants (DFGs) (Age UK, 2013d, Communities and Local Government, 2013). These grants may be used for ATs and housing adaptations to make an environment safer and to enable access to essential areas and facilities within their home (Adams, 2015). The decision to provide a Disabled Facilities Grant (DFG) is made by the person's Local Authority (LA) housing department, which means tests their eligibility. Once again, the means test takes into account the income and savings of the person with dementia, although disability benefits below £6,000 per annum are excluded from the test. When a person with dementia is eligible for a DFG, the social services and housing departments within the LA liaise to decide which housing adaptations will be provided (Age UK, 2013d). In England, the maximum DFG is £30,000, although the average provision is approximately £6,500 (Adams, 2015). Again, provision differs across the UK countries; for example, the threshold is £36,000 in Wales, up to £25,000 in Northern Ireland, and not available at all in Scotland (Age UK, 2013d, gov.uk, 2015).

People with dementia are additionally entitled to receive appropriate ATs and other adaptations to their home under the Chronically Sick and Disabled Persons Act (1970) (Age UK, 2013b, Age UK, 2013d, UK Parliament, 1970). Even if a person is having difficulty obtaining a DFG, social services still has a duty to provide this assistance. People with dementia may also be entitled to other financial supports such as Attendance Allowance if aged over 65 years, Pension Credit, Council Tax Reduction, or Personal Independence Payments if they are under 65 years of age (the latter was previously known as Disability Living Allowance) (Age UK, 2013e, Department for Work and Pensions, 2015). Informal carers may be eligible for Carer's Allowance of £62.10 a week (2016-2017 proposed rates) to help care for someone (Department for Work and Pensions, 2015), but this may affect other

benefits they or their care-recipient receives (Age UK, 2013a, Age UK, 2013e). Some of these will be taken into account during means tests (Age UK, 2013a, UK Parliament, 2014). The eligibility criteria for these benefits and entitlements will not be further discussed in this thesis. The focus now turns to the sources from where people with dementia and their carers may obtain ATs for ADLs.

2.7.6: Obtaining ATs via social services or private means

Some ATs, such as commodes and walking aids, are considered healthcare technologies so are provided free from hospitals, General Practitioners (GPs), and district nurses (Age UK, 2013b). Other ATs are considered under social care services. In England, 150 LAs provide funded ATs and minor environmental adaptations for people's homes (Department of Health, 2011). Equipment and adaptations available from social services include: stair lifts, accessible showers, stand-aid hoists, hand-rails, and kitchen utensils. Again, provision is subject to the person's country of residence. English residents may receive funded ATs up to a cost of £1,000 under The Community Care (Delayed Discharges) Act (2003) (Age UK, 2013d, UK Parliament, 2003). In Wales, AT provision is based on a means-test so the £1,000 threshold does not apply, and people in Scotland and Northern Ireland are usually able to receive the ATs they need for free (Age UK, 2013a, Age UK, 2013b, Age UK, 2013d). There are, however, some problems with obtaining equipment as there are no legal waiting times within which equipment must be provided once eligibility has been determined (Age UK, 2013b). Very little is currently known about who receives ATs from English LAs. Brittle et al. (2007) explored receivers of social service funded ATs and adaptations and discovered that over half were female, and more than three-quarters were aged 65 years and older. Most of the ATs were to assist with bathing ADL. However, the authors did not measure the cognitive function of recipients. Whilst it is useful to understand the types of devices provided, these results are not necessarily generalisable to those with dementia.

Although funded ATs are available (Age UK, 2012c), many older people have been known to privately purchase them (Department of Health, 2011). For those aiming to obtain ATs privately, Age UK (2013b) have published information on where potential users can purchase suitable equipment. These include: private AT companies in shops or via their mail-order catalogues; chemists; websites of voluntary and charity organisations such as Age UK, Alzheimer's Society, and Disabled Living Foundation; Independent Living Centres; or second-hand via newspaper adverts or social networks (Age UK, 2013b). People with disabilities and those with dementia who have been assessed as having care needs are Value Added Tax exempt when purchasing specialist equipment for their own use; hiring disability equipment; and when paying for building work to adapt their own home (Age

UK, 2013b). The extent to which people with dementia and their families privately purchase ATs is currently unknown. The third research question of this project was to explore the barriers, preferences, and facilitators to AT use of informal carers; this includes how they received information on technologies, identified what they needed, and sourced appropriate devices.

2.8: The institutionalisation of people with dementia

Unfortunately, ATs are not always able to meet a person with dementia's every need; in Chapter 5 the difference between underlying disability and residual disability is illustrated (Agree and Freedman, 2003). Underlying disability is the impaired performance of an ADL as a result of cognitive, physical, and environmental restrictions. Residual disability refers to difficulties that remain even when the person has human and technological assistance. It is residual disability when performing ADLs that may be hypothesised to increase the likelihood of institutionalisation, the act of moving permanently into a care home (Horgas and Abowd, 2004). As such, the fourth research question of this study was to explore the tipping points for a relocation of care and whether ADL performance and AT use contributed to that decision. Within this, of particular interest was whether carers perceived use of ATs delayed institutionalisation.

Scholars of person-centred care recognise that dementia is a pathological bodily state (Innes, 2009, Kitwood, 1997a), but argue that the experience of dementia is influenced by more than biological factors in that it also includes environmental, social psychological, and life course factors (Kitwood, 1997c). By considering such factors, a person with dementia can be supported to live well in any location; while many people with dementia would prefer to remain living at home, many are able to live well in care homes with well-trained staff even if this was not their preferred location of choice (Vittoria, 1998). Both institutionalisation decisions and living well when residing in a care home are addressed further in Chapter 5. This also links to the fifth and final research question in this thesis; to explore ADL performance and associated AT use of people with dementia who reside in care homes, and whether AT use could enhance relationships between individuals.

2.9: Chapter 2 summary

In summary, dementia is a condition that can severely affect a person's cognitive and physical functioning to the extent that they may be unable to perform ADLs without assistance. The performance of these daily activities is also influenced by the person's physical, social, and cultural environment. As there is currently no cure for dementia, the only form of intervention is human and

technological assistance to help the person with dementia to manage their ADLs. An exploration and understanding of the contribution that use of ATs can make is critical as not only can they assist ADL performance but contribute to a user's sense of living well with choice. Some people may be eligible to receive state-funded formal care services, ATs, and environmental adaptations. However, it is acknowledged that even with human and technological assistance, there may come a time that the person with dementia must relocate to a care home to ensure their safety. The following three chapters present a comprehensive scoping review of literature on these topics, using empirical evidence to support or refute what is currently known. The gaps in knowledge that elicited from the review of published literature were used to shape the research questions of this thesis.

Chapter 3: Dementia and ADL disability

In the first section of Chapter 3, the strategy used to search for and appraise relevant papers for the scoping review of literature is presented. This includes a numerical analysis conducted on papers, and a discussion on the presentation of appraised literature in Chapter 3. The main focus of this chapter concerns the examination of literature exploring how ADL disability occurs among people who have dementia. An overview of the disablement process model is first presented, as it is used in this thesis as the theoretical framework to understand how dementia may lead to ADL disability. This model was chosen as it draws on both the biomedical and social perspectives of disability to explain the cognitive, physical, and environmental factors that influence the pathway from pathology to disablement. A clear understanding of how dementia leads to ADL disability is important as research questions 1 and 5 in this thesis explore how people with dementia experience difficulties performing ADLs in community and care home locations respectively. The discussion of this model is followed by a detailed examination, drawing on empirical research to date, of how dementia affects the ADLs introduced in Chapter 2: bathing and washing; grooming and dressing; toileting and continence; and feeding and eating (Katz, 1983). A key knowledge gap arising from the review of this literature is presented; a lack of focus on the specific tasks and actions which might indicate 'poor ADL performance' in research rhetoric.

A modified version of the disablement model is then presented, which elaborates on how ADL disability may be helped or alleviated by extra-individual factors. Conceptual overlap between the disablement process model and the person-centred approach to dementia care is then considered. The two extra-individual factors of interest are: personal assistance through human care, and special equipment and devices such as ATs. How human care from family members (informal carers) or paid staff (formal carers) helps people with dementia to perform ADLs is examined in this chapter. Attention is also given to the barriers faced by people with dementia and their informal carers when accessing formal care services.

3.1: The scoping review - search strategy and critical appraisal

In this section, the topics within the scoping review of literature are outlined, and the scoping review approach is justified. The search strategy conducted to identify papers and the exclusion criteria applied to reject irrelevant literature are described below. The reader is also directed to the Appendix for supporting information on the search strategy. Then, summary tables used to extract key information from the relevant literature are discussed. The numerical and thematic analyses

used to critically appraise the article contents are described. The results from the numerical analysis are then presented. The final section outlines the presentation of the thematic analysis findings throughout Chapters 3, 4, and 5.

3.1.1: Scoping review topics

The topics framing the review of relevant academic and grey literature aligned closely with the five research questions presented in Chapter 1. These topics covered the following five areas: the cognitive and physical difficulties experienced by people with dementia when performing ADLs in the community; the types of ATs used by people with dementia and their informal and formal carers in community settings; carers' preferences, barriers, and facilitators with respect to the use of ATs by people with dementia in community settings; the tipping point for the person with dementia in relocating to a care home, and its relationship to how institutionalisation decisions are made; and ATs used by and with people with dementia in care home settings, and the contribution of AT use to connections between residents, staff, and families. While these topics covered different research areas, the literature search focused on identifying papers that covered three core themes for this thesis: dementia, performance of ADLs in community or care home settings, and assistance from carers or ATs for ADL performance.

3.1.2: Scoping review approach

A scoping review was deemed the most suitable framework to appraise the literature due to the broadness of: the three core themes among the five topics of interest described above; the multiple study designs and methods used to explore these topics (for example, cross-sectional dataset analysis, observational techniques, and pre-and post- intervention data); and different types of papers to be reviewed (both peer-reviewed academic papers and grey papers were to be included) (Arksey and O'Malley, 2005). A systematic review was deemed an inappropriate approach for this exploratory study, as the aim was not to answer narrow research questions using a small number of quality studies of the same design (Arksey and O'Malley, 2005). Rather, the aim of the scoping review was to numerically and thematically analyse all types of relevant academic and grey literature to identify research gaps in current evidence and understanding (Arksey and O'Malley, 2005, Armstrong et al., 2011, Mays et al., 2001). However, the search strategy to identify appropriate peer-reviewed academic papers was systematic, described below.

3.1.3: Literature search strategy – three phases

The search to identify relevant literature for the scoping review consisted of three phases. Phase One consisted of searching systematically for literature; Phase Two for applying exclusion criteria to the literature; and Phase Three for identifying and incorporating grey literature into the scoping review. A summary flowchart of the three phases of the search strategy is presented in Appendix 2 which presents more detail such as: the names of databases used; number of searches within them, and number of potentially relevant papers.

3.1.3.1: Phase One

Phase One concerned identifying peer-reviewed academic papers, such as: empirical research articles, literature reviews including systematic reviews, conceptual and theoretical papers, and books. To obtain these, a search was conducted across 21 electronic databases and two websites. These databases and websites were selected because their subject areas were deemed relevant for this study, for example: social sciences, gerontology, psychiatry, or psychology. Keywords and phrases used to search within these databases and websites covered topics including: ADLs, dementia symptoms, physical difficulties and functionality, and ATs. Relevant empirical research articles that employed case study strategy to explore dementia and AT use were also of interest, so words linked to methods and methodologies were used. When searching, the asterisk (*) was used as a wildcard character to search for multiple endings of keywords. For example, 'institution*' was used to search for the words 'institutionalisation' and 'institutionalised'. A comprehensive table of the keywords and phrases used to identify the relevant literature is in Appendix 2. Following standard practice in scoping reviews (Arksey and O'Malley, 2005), literature was also found through hand-searches of hard-copy journals in the King's College London libraries, and using publication reference lists from key articles. Literature unobtainable in English was immediately excluded. In total, this literature search resulted in 683 potentially relevant peer-reviewed academic papers.

3.1.3.2: Phase Two

Phase Two of the search strategy concerned examining the 683 papers and applying four main exclusion criteria to reject irrelevant literature. The first exclusion criterion was to exclude papers concerning people who lived outside of Europe or Northern America, as cultural values and social care systems may vary considerably across different regions (Hayashi, 2013, Man-fuk Leung, 2000). However, it is acknowledged that social care services also vary across and within Northern American and European countries; this is even the case when the countries that make up the UK are considered as was highlighted in Chapter 2. Thus, the thematic findings from this scoping review

were carefully considered for whether the results would be meaningful for English dementia policies and population. The second criterion excluded papers that were clinical in nature, such as that relating to: healthcare, medical technologies, drug treatments, or using clinical research field-sites such as hospitals and hospices. This was because this study focused on community-based and care home locations, and the social care rather than medical or healthcare provided there. The third criterion for exclusion related to ADL disabilities for non-dementia populations such as cognitively-healthy older adults, or people with other types of cognitive impairment. This enabled the scoping review to be focused on the population under investigation. However, it became apparent during the appraisal of papers that, for some relevant topics, there was no research focused on people with dementia. Thus, it was necessary to include some papers on physically-frail but cognitively-healthy older adult populations where appropriate. That, for some topics of interest, relevant research had not been conducted with participant populations with dementia was the main finding in the scoping review. The fourth and final exclusion criterion was to remove studies on ATs and other technologies not specific to ADL performance. Thus, studies on telecare and telehealth were excluded; descriptions of these technologies are in Chapter 4.

3.1.3.3: Phase Three

Phase Three of the search strategy included the identification of non-peer reviewed but relevant and informative grey literature. They included, for example: social care white papers and governmental reports; reports from stakeholders such as national charities; charity factsheets; and AT booklets. These were procured sporadically throughout this study via online and offline sources including: key government websites, conferences, materials from GP (General Practitioner) waiting rooms, AT catalogues in field-site care homes, or from colleagues. They were incorporated into the scoping review, where appropriate, to aid understanding and set the topics in policy and practice contexts (Anderson et al., 2008, Levac et al., 2010).

3.1.3.4: Additional literature identified throughout this study

In addition, short searches were sporadically conducted throughout the study to identify any recently published literature of relevance for this study. Thus, the scoping review chapters were living documents until thesis submission, and the final versions contained article references other than those identified through the three Phases described above. The critical appraisal presented below concerns the literature referenced in the final versions of the scoping review chapters in this thesis. They consisted of 301 peer-reviewed academic papers and 31 grey papers. Details of the numerical and thematic analyses which formed the scoping review are presented below.

3.1.4: The process of appraising relevant literature

Each of the 332 academic or grey papers referenced in this scoping review was appraised for key information. This was input into a summary table identifying, where appropriate: the type of literature (for example, empirical research article, theoretical paper, charity factsheet, and so on); location of authors or where data were collected; the aim; the population of interest or who participated; the AT type under consideration; the design; key findings; and implications for this thesis including why it was referenced throughout the scoping review chapters (Chapters 3, 4, and 5). The strength of evidence was also indicated in the design column of the table. That is, whether there was an experimental, quasi-experimental, or non-experimental design, and whether data analysis was cross-sectional or longitudinal. Whilst generally an assessment of the strength of research is not included in the remit of a scoping review (Arksey and O'Malley, 2005, Armstrong et al., 2011), it was felt useful to aid the critical appraisal of papers. Summary tables were used to enable logical recording of the details of each paper and to allow the scoping review to be shaped by a thematic framework, even though evidence was not to be synthesised in a systematic review (Arksey and O'Malley, 2005). There were 10 summary tables in total which covered the five broad topics outlined in section 3.1.1; for each topic there was one summary table for peer-reviewed academic papers and one summary table for grey papers. The first page of the first review table is presented in Appendix 2 to illustrate the content of the tables. The 10 review tables are not included in full in the Appendix as they span 90 pages; too many to enable hard-copy binding of this thesis. However, they are available on request from the author.

The scoping review followed the 'Arksey and O'Malley framework' for collating and reporting the data and findings (Arksey and O'Malley, 2005, Levac et al., 2010). That is, first a numerical analysis of the nature of the referenced literature was conducted to identify the types of papers published within each topic of interest. Second, a qualitative, thematic analysis was conducted to understand the topics and to recognise gaps in knowledge. Identification of themes enabled exploration of the evidence without necessarily describing the design and findings of each research article in detail, as may occur in a systematic review (Armstrong et al., 2011). Rather, the thematic analysis identified implications for future research (Levac et al., 2010); thus, outcomes of this scoping review were the finalisation of the research questions and design of this study.

3.1.5: The numerical analysis findings

The numerical analysis involved extracting raw frequency data from the 10 summary tables for multiple variables of interest. These variables were: the country of origin; the year of publication; and the focus of literature. Focus of literature included: the type of paper; the population; data; design; analysis; and whether literature reviews and conceptual papers had described the search strategy to identify relevant articles. For each variable, frequencies were counted and percentages were calculated. Percentages were rounded to the nearest whole number. The percentage summary tables are presented in Appendix 2, and raw data tables are available on request from the author. Overarching numerical summaries and discussions on the 332 referenced pieces of literature for each topic are presented below.

3.1.5.1: Country of origin

The countries or areas within which empirical research had been conducted, or from where authors were based, were noted. The USA, UK, and Canada made up the bulk of referenced literature, forming 39%, 27%, and 8% of the referenced peer-reviewed academic papers respectively. Together, these areas formed 74% of referenced literature. This was expected given that the search strategy excluded articles based on people living outside of Europe or Northern America, with the justification that social care systems vary considerably across different regions. Also, only literature that could be sourced in English was included, thus potentially excluding relevant publications in other languages. Arksey and O'Malley (2005) also advised that most electronic databases have a Western bias, particularly towards publications from the USA. This American focus is a limitation as knowledge cannot easily be generalised to the UK population, particularly when policy differences such as the Medicaid and Medicare programmes in the USA contributed to an article's results. For example, it is unlikely that the cognitive and physical pathway to disablement of people with dementia differs between the UK and USA; yet as disability is also influenced by the person's physical, cultural, and attitudinal environment (Nagi, 1965, Nagi, 1991), differences in overall disability 'status' between the two may indeed occur. However, the aim of the scoping review was to identify gaps in knowledge and understanding; a bias towards publications from the USA exemplifies the need for similar and greater research on individuals with dementia residing in England and in the UK. Concerning referenced grey literature, 87% were from the UK. This was expected given that most were UK governmental policies and papers, charity reports, and charity factsheets.

3.1.5.2: Year of publication

The year of publication was analysed. Of the 332 papers, 287 (86%) were published within the last 20 years, from the year 1997 and onwards. All grey literature was included in this figure. The 45 (14%) peer-reviewed academic papers published in 1996 or before were examined more closely, and notes on these are included in Appendix 2. On viewing results, much of the older referenced literature was included because it covered the theoretical basis for this thesis at the beginning of Chapter 3. This included: the biomedical approach to understanding disability in 1992, the Nagi disability model in 1965 and 1991 and the disablement process model from 1994, and some references for how cognitive and physical impairments and functional limitations impact upon the body. Older references from 1973 and 1982 for explaining environmental-pressure upon a person with disability were also included in topic 4 at the beginning of Chapter 5 on the institutionalisation of people with dementia. Older theoretical and conceptual literature was referenced because it is necessary to reference the original publication on a topic rather than relying on a later paper that refers to it, to ensure misinterpretation has not occurred (Jesson and Lacey, 2006).

3.1.5.3: Focus of literature

Approximately 91% of the referenced literature consisted of peer-reviewed academic papers, meaning approximately 9% were grey papers. Within the peer-reviewed academic papers, 60% were empirical research articles, 30% were theoretical or conceptual papers including literature reviews, and 10% were books or book chapters. Concerning the strength of literature, further analysis on the 181 empirical research articles demonstrated that most (88%) were non-experimental and only 6 had an experimental design. There were few randomised controlled trials or other studies with experimental design investigating relevant ATs. This could reflect the assumption demonstrated in the National Dementia Strategy (Department of Health, 2009) that ATs for ADLs are beneficial, or merely that experimental studies are difficult to conduct. Approximately 69% of empirical research articles used quantitative data only, 27% qualitative only, and 4% used a mix of both types of data. Data analysis of quantitative data was similarly split between cross-sectional and longitudinal designs. The largest number of newly-referenced qualitative articles occurred in topic 3 which corresponds to carers' preferences, barriers, and facilitators towards AT use. This finding could be expected given that this topic explores opinions, attitudes, and experiences.

Populations under investigation in the empirical research articles were mostly: people with dementia (22%); older adults experiencing physical disability but without dementia (23%); and informal carers of people with dementia (15%). A further 23% investigated combinations of different

populations, which included: caring dyads (the care-recipient and their informal carer), people with different types of dementia, and people with dementia compared to matches with no cognitive impairment. Some similarities were demonstrated in the conceptual papers category: 48% were on people with dementia and 18% concerned older adults with disability but without dementia. In addition, seven referenced papers focused on technologies rather than people, and these were all referenced in Chapter 4 on ATs for ADLs. People with disabilities of any age were more of a focus for the conceptual papers and books compared to the empirical research articles. Only 20% of the conceptual papers described their search strategy to identify relevant literature; which was surprising given that this category included systematic reviews. Few of any type of peer-reviewed academic paper investigated formal carers, health professionals, and social care staff; this is discussed as a gap in knowledge in Chapter 5.

3.1.6: Presentation of the thematic findings throughout Chapters 3, 4, and 5

The thematic analysis of this scoping review highlighted multiple key knowledge gaps: task specific difficulties people with dementia had when performing ADLs was unknown; no evidence on the ATs being used by people with dementia and their carers in community-settings; no data on how people with dementia begin to use ATs; where people obtained ATs including the role of formal services in accessing them was unknown; no information on how use of ATs was maintained; no evidence on informal carers' perceptions of their role concerning ADL performance and AT use; no data on the role of ATs for ADLs towards relocation triggers and decisions concerning people with dementia; and no information on when and how ATs are used for ADLs in care homes for people with dementia including the extent to which they contribute to relationships between residents and carers.

The presentation of thematic findings within the appraised literature was divided into Chapters 3, 4, and 5. Chapter 3 contains literature describing how ADL disability may occur in people with dementia using the disablement process model. It includes how human carers may provide assistance with ADL performance to people with dementia. In Chapter 4, the different ATs to assist performance of the ADLs under investigation are introduced. The discussion then concerns literature on carers' perceptions, barriers, and facilitators to appropriate AT use. In Chapter 5, triggers for institutionalisation are identified, and literature on decision-making around relocation of care is discussed. Then, work aimed at understanding care home life not only for people with dementia, but for their families and care staff is presented. Table 1 below illustrates the flow of development from the broad topics of interest, to the key knowledge gaps identified in the scoping review, and on to the finalised research questions.

Table 1: The pathway from broad topic to research question, resulting from the scoping review

Topic number	Topic	Key gap in knowledge identified in the scoping review thematic analysis	Contributed to finalisation of research question:	Discussed in Chapter:
1	The cognitive and physical difficulties experienced by people with dementia when performing ADLs.	No task specific difficulties in ADLs known.	Research question 1	Chapter 3
2	The types of ATs used by people with dementia and their informal and formal carers in community settings.	No data on what ATs are actually being used in the community outside of research studies to test devices.	Research question 2	Chapter 4
3	Carers' preferences, barriers, and facilitators to the use of ATs in community settings.	No data on how people with dementia begin to use ATs, where they are obtained including the role of formal services, how use of ATs is maintained, and carers' perceptions of the role of ATs.	Research question 3	Chapter 4
4	The tipping point for the person with dementia to relocate to a care home, and how institutionalisation decisions are made.	No data on whether institutionalisation triggers (statistical) include AT use/non-use among people with dementia, and no data on whether decision making (conceptual) for institutionalisation incorporates current or future AT use.	Research question 4	Chapter 5
5	Identifying ATs used in care home settings, and contribution of their use to connections between residents, staff, and families.	No evidence on which ATs are used in care homes, when they are used, and how they are used. No data on family relationships in care homes.	Research question 5	Chapter 5

Table 1 also guides the reader to the thesis chapters within which the key gaps are discussed. To illustrate: it can be seen from Table 1 that the fourth topic concerned the institutionalisation of

people with dementia; the tipping points for such an event and decision-making concerning relocation. The thematic analysis identified that research on this topic could be divided into quantitative evidence identifying statistically predictive triggers for institutionalisation for people with dementia, and conceptual and qualitative evidence on decision-making for institutionalisation of people with dementia. It was further observed that within both of these two types of research design, evidence for the contribution of ADL disability to institutionalisation was mixed and the use of ATs was rarely acknowledged or investigated. Thus, research question 4 was finalised; all final research questions are presented in Chapter 1. It is then indicated in Table 1 that the gaps in knowledge identified for the fourth topic are presented in Chapter 5.

The scoping review thematic analysis findings and discussion sections in each chapter are preceded by a section outlining the presentation of reviewed literature that follows. There is one presentation section for each of the five topics. In each of the presentation sections, justification is given for the inclusion of literature which was used to support the arguments. This ensures that a critical eye is turned onto why reviewed articles were selected and referenced. The first of these presentation sections is below and relates to the literature referenced in Chapter 3 for the first topic of interest.

3.2: Presentation of reviewed literature for topic 1

Sections 3.3 to 3.8 of Chapter 3 cover the scoping review of literature for the first topic: the cognitive and physical difficulties experienced by people with dementia when performing ADLs in the community. During the appraisal of literature for this topic, it was deemed necessary to outline a theoretical approach to understanding how ADL disability occurs for people with medical conditions. This is presented in section 3.3. As the disablement process model was chosen, papers discussing this were typically older, conceptual in nature, and from the USA. Papers referenced to support individual components of the model were chosen based on relevance and the strength of evidence as noted in the study design column of the summary tables which noted key information from each referenced paper.

The theoretical approach to understanding disability sets the context for the discussion in section 3.4 on the empirical evidence exploring how ADLs are affected among people with dementia specifically. Papers for this section, mostly empirical research articles, were chosen for their relevance to each of the ADLs under investigation, and their focus on people with dementia rather than on other populations. In sub-section 3.4.5, the key knowledge gap that was identified from the thematic

analysis of literature is discussed; that task specific difficulties people with dementia had when performing ADLs was largely unknown. That is, empirical and theoretical research that was reviewed to date had typically focused on broad terms for ADLs without identifying the individual actions with which people with dementia had difficulty. In addition, research concerning people with dementia also tended to focus on challenging behaviours rather than ADL performance. Thus, for some key points, it became necessary to reference research on non-cognitively impaired older adults in order to present evidence of ADL disability. The application of this evidence to populations with dementia may be queried, hence research question one for this study was designed.

Following this, a modified model of the disablement process is referenced in section 3.5. This theoretical discussion again necessitated the inclusion of older papers, and those largely from the USA. Given that this also concerned the introduction of social care to support ADL performance, some relevant grey papers were also referenced to refer to the UK context. The conceptual overlap between the disablement process model and the person-centred care approach is then discussed in section 3.6. No empirical research and no conceptual or theoretical papers comparing their similarities and differences could be sourced. Instead, all references in this sub-section were conceptual papers on either the disablement process model or person-centred approach to dementia care. The content of these papers were analysed for areas of conceptual overlap. The discussion then turns to human assistance for ADLs in section 3.7, and 3.8 includes barriers that may occur for people with dementia and their carers when accessing formal care services. Although the key paper referenced for this discussion on barriers was based on secondary data analysis from Australia (Brodaty et al., 2005), it was used because it was the strongest of few relevant papers which concerned carers of people with dementia rather than other conditions. Therefore, it was the most relevant of all papers that had been reviewed, and was useful when designing interview questions and prompts for carer-participants in this study.

3.3: The disablement process: a pathway from dementia pathology to ADL disability

In this section, first brief explanations of the two major understandings of disability are given. These are the biomedical and socio-environmental perspectives. Both are criticised for failing to fully explain how disablement occurs among people with dementia, and particular, how the use of ATs fit in. The discussion continues with the introduction of the disablement process; a model which

straddles these two perspectives on disability. The disablement process model is examined in relation to dementia.

As indicated in Chapter 2, a person diagnosed with any type of dementia is categorised into a mild, moderate, or severe stage of the syndrome. This is a biomedical approach to dementia as it focuses entirely on the internal bodily processes within a person that affects ADL performance (Innes, 2009). Dementia is progressive, meaning that cognitive and physical impairments will become more pronounced; therefore, so too will performance of ADLs become more affected over time (Davies et al., 2009). In the biomedical view, disability is perceived as a gap between the person's ability to perform the required actions and the demands of the particular activity (Brandt Jr and Pope, 1997). For example, a person with dementia performed a transferring movement from sitting in their armchair to standing upright. He or she stood up unsafely, fell, and sustained a serious injury. Following this incident, he or she was continually monitored by his or her carers and instructed not to stand when alone. The carers perceived the problem to have been the person's poor immobility; so the blame for the injury was attributed to the person with dementia's body. Yet, this biomedical approach has been criticised by proponents of a social model of disability for attributing all poor ADL performance to the pathology of the syndrome known as dementia, and ignoring the influence of the environment (Bond, 1992, Thomas, 2007).

The socio-environmental model posits that disability is not only caused by the body's inability to perform an action, but that it is largely influenced by the physical, architectural, socio-cultural, financial, and attitudinal environment in which the person is situated (Downs, 2000, Gannon and Nolan, 2007, Scherer et al., 2007, Thomas, 2007). As such, the disability a person experiences depends to a large extent on a supportive or unsupportive environment (Thomas, 2007). Using the same transferring example as above, instead of blaming the bodily abilities of the person, the carers attributed the fall to an unsafe and unsuitable environment, such as an unsupportive armchair.

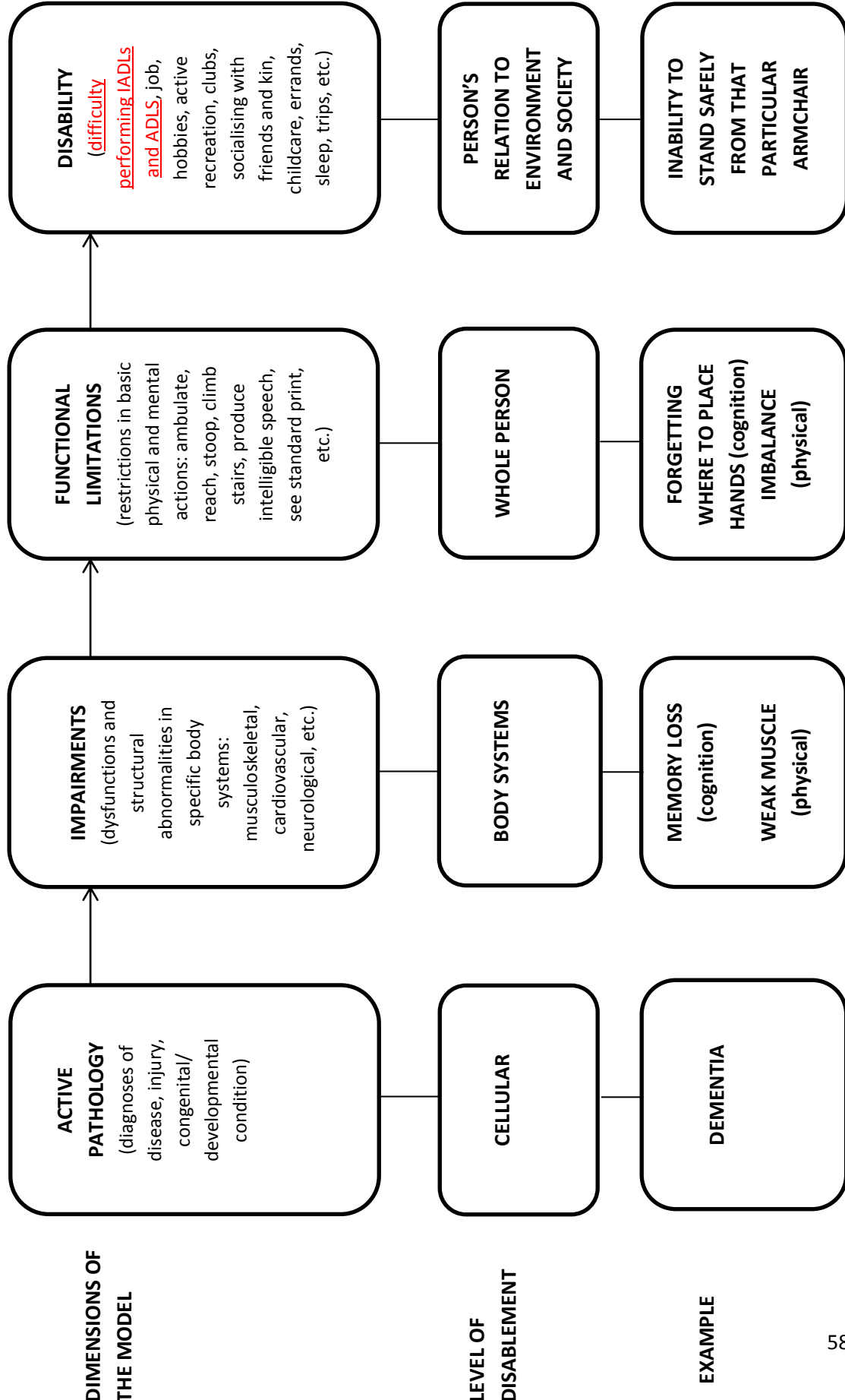
Both the biomedical and socio-environmental frameworks of disability promote the use of ATs to assist a person to perform the actions needed to complete an activity (Thomas, 2007). For example, the person with dementia who stood up and fell may have benefitted from the use of a walking frame and elevated armchair feet to help them to stand safely. While the biomedical model would perceive the ATs as enhancing the physical capabilities of the person with dementia, the socio-environmental perspective would consider the devices as altering the environment to become more suitable. On a practical level the devices were still used; the difference was only the theoretical lens

through which the observer viewed and interpreted the use of ATs. Indeed, researchers agree that the use of ATs may both expand the capabilities of a person's body (as in the biomedical view), and act to reduce environmental demands (as in the socio-environmental perspective) (Agree and Freedman, 2003). Therefore, the process of becoming disabled and consequent use of ATs for ADLs may best be understood using a socio-medical model of disability that merges the biomedical and socio-environmental perspectives (Allen et al., 2001).

The disablement process developed by Nagi (1965, 1991) is such a socio-medical model. It proposes ADL disability to be caused both by the body's inability to perform certain actions and by environmental limitations. Nagi's model illustrates how pathology, such as dementia, affects a person's body through a progressive pathway from initial cognitive and physical impairments, to functional limitations, and on to poor performance of ADL tasks (termed disability). It also recognises contextual factors; that is, that the environment combines with functional limitations to help or hinder ADL performance and thus lead to disability. An illustration of the disablement process pathway with dementia-related examples is presented below in Figure 1 (Nagi, 1965).

According to the disablement process model shown in Figure 1, the cellular changes and pathological state of dementia lead to abnormalities in bodily systems. These are called cognitive and physical impairments. The cognitive processes that dementia can impair include: long-term memory, working memory (short-term storage of task-specific information), executive functioning (the ability to plan and implement a sequence of physical actions), inhibitory control (the ability to suppress irrelevant behaviour), and verbal fluency (Johns et al., 2009, Mihailidis et al., 2004b, Wherton and Monk, 2008). Physical impairments include: poor balance, muscle weakness, tremors, and apraxia (whereby the person cannot put the right muscle movements together to perform the task even when the command is heard and understood) (Robinson and Fisher, 1999, van Hoof and Kort, 2009, Verbrugge and Jette, 1994). The brain may also misinterpret signals from the body, reducing nerve reaction times and causing sensory impairments in visuo-spatial, auditory, and olfactory domains (Behrman et al., 2014).

Figure 1: The disablement process model



The disablement process model proposes that the cognitive and physical impairments described above lead to functional limitations: the inability to perform appropriate actions at whole body level (Lawrence and Jette, 1996). These again are categorised into cognitive and physical domains. Cognitive functional limitations include poor verbal communication, inability to learn new tasks, difficulty recalling a word list, and being disoriented to time and place (Barberger-Gateau et al., 2002, Belleville et al., 2007). Physical functional limitations may be perceived under the terms 'immobility' or 'poor mobility' and include: reduced walking speed, impaired balance, reduced grip strength, and pain on movement (Baloh et al., 1995, Buchman et al., 2007, Rosano et al., 2005). Reduced satiety and damaged swallow reflex are also observed (Camicioli et al., 1999). These cognitive and physical functional limitations will be illustrated using the transferring example presented earlier. First, the person with dementia displayed a cognitive functional limitation because he or she forgot where to place their hands on the armchair to push sturdily; poor memory alone would be considered a cognitive impairment, whereas forgetting where to place the hands on the armchair transforms it into a functional limitation. Second, physical functional limitation was exhibited when his or her brain missed important bodily cues about the balance of their pelvis and placement of their legs. The combination of these cognitive and physical functional limitations led the person with dementia to over-estimate the force of movement required to stand safely.

Further, the disablement process model considers functional limitations to be generic tasks or actions leading to disability only when those actions are undertaken together to perform a socially-defined activity, such as an ADL (Jette, 2009). This relates to the final box in the pathway of disablement illustrated in Figure 1, which highlights ADLs as one of many types of socially-influenced activities. The model posits that a person may have poor performance in some of the actions required to complete an ADL, but it is only in combination with certain physical, social, and attitudinal contexts that disability truly occurs. Therefore, the environment has a significant enabling or disabling effect on the completion of each activity. Continuing the transferring example, the person with dementia performed the transfer task in the living room of their care home, where all armchairs were standard models and not ergonomically fitted to his or her needs. The armchair was low to the ground, with slippery hand rests, and a soft base and back; all of which contributed to an unsupported starting position and poor grip. In a different room, with a different armchair, the person may not have fallen, even if they were as unsteady when standing up from sitting. Thus, according to the disablement process, both the person's bodily (cognitive and physical) processes and the environmental context contributed to the acute incident: the fall.

It is important to understand the extent to which bodily and environmental processes individually and in combination contribute to poor ADL performance to determine how best to provide appropriate dementia care services. For example, consider the ADL of washing hands after evacuating the bowels. Washing hands is important in order to maintain hygiene and prevent cross-contamination of harmful bacteria to others (Ziady and Small, 2005). Potential task errors caused by impaired cognition relate either to: failure to perform a step (for example, the person could forget to use soap), or performing a step inaccurately (such as using too-cold water) (Beck et al., 1993, Bennett et al., 2002, Vitaliano et al., 1986). A cognitively-healthy individual can recognise when, how, and why they have made a task error, and are able to take actions to correct themselves (Giovannetti et al., 2008). People with dementia, however, eventually become unable to recognise, react to, and correct their mistakes (Roy et al., 2011). The person's physical functional limitations may also contribute to poor performance of hand-washing activity. For example, they may be unable to mobilise safely to the sink or be strong enough to turn the taps on. Finally, the person's environment could contribute to poor task performance. For example, the sink could be too high or too low for the person, or it could be the same colour as its surrounding walls and be unnoticeable to the person with dementia. By understanding the precise difficulties each individual with dementia has when undertaking each specific task, carers can appreciate the person's remaining capabilities. This will enable them to assist only with those actions, only when necessary. This encourages dignity, prevents over-caring, and promotes person-centred dementia care (Department of Health, 2009).

3.4: Decline of ADL performance among people with dementia

Also important to the design and provision of quality care is an understanding of the degradation of ADL performance among people with dementia specifically, compared to others with ADL disability who do not have dementia. The disablement process model has been demonstrated to apply to dementia-related disability (Barberger-Gateau et al., 2002). Overall, once immobility and poor transferring movements are present, both people with and without dementia display a predictable order of difficulties with the socially-defined activities. First to be affected are the complex IADLs such as: managing money, shopping, and preparing food. Then, over time, the more basic ADLs become impaired (Kingston et al., 2012). Research has further demonstrated a distinct pattern of decline amongst these ADLs (Gillette-Guyonnet et al., 2011, Gillioz et al., 2009, Lechowski et al., 2010). Often, the first activities to be affected are washing and hygiene, followed by grooming and dressing, and then toileting and continence. Feeding and eating are the last activities to be affected.

The pattern of decline also loosely links to the stages of the syndrome; difficulties become more apparent as people progress from mild to moderate to severe dementia (Hughes et al., 1982).

People with dementia have been shown to experience decline in ADL performance significantly sooner than their cognitively-healthy counterparts owing to the addition of cognitive impairments (Mihailidis et al., 2004a, Mihailidis and Fernie, 2002). To illustrate, a cognitively-healthy older adult may become physically frail and have difficulty holding cutlery, but is unlikely to additionally forget how to use a spoon and how to swallow food, as may happen to a person with dementia. Therefore, there are greater circumstances by which ADL performance could be impaired among people with dementia. Empirical evidence concerning how performance of each ADL may be impaired for people with dementia as a result of bodily or environmental factors is presented in the sub-sections below.

3.4.1: Bathing and washing

Washing is an important self-care activity for maintaining good health, hygiene, and appearance. Most research on washing and bathing ADLs among people with dementia has focused on interventions to reduce challenging behaviours such as agitation and verbal or physical aggression (Dunn et al., 2002, Namazi and Johnson, 1996, Sloane et al., 1995). People with dementia may display these behaviours because they may be frightened and anxious about, for example, deep water, showerhead noise, water temperature, and the possibility of being locked in the bathroom (Alzheimer's Society, 2013g, Reisberg et al., 1985). Their concerns may relate as much to the person's environment as to the cognitive and physical functional limitations resulting from the dementia pathology.

Research describing how and why bathing, showering, and washing activities may be difficult for people with dementia is limited. That is, no evidence was found in the scoping review to explain the contributions of cognitive, physical, and environmental factors on the performance of washing, bathing, and showering activities. Yet, these three factors may contribute individually and in combination to this specific ADL disability. For example, to bathe alone without human or technological assistance requires an understanding of how to use taps and perceive an appropriate water level and temperature. It requires being mobile enough to step into the bath safely and being flexible enough to wash the body fully. It necessitates an understanding of how to use soap, shampoo, a flannel, and other accessories. It requires strength to lift the body, and balance to step out of the bath safely without slipping. It means remembering not to stay in the bath until the water is cold, how to clean and dry all body parts, and how to empty the tub of water when finished. This

example shows that for a 'simple' and 'basic' activity such as bathing there are multiple sub-tasks that require a great deal of cognitive and physical capacity to plan actions and interact with an appropriate and supportive environment. To date, no research articles have examined such bathing steps in detail in relation to people with dementia.

3.4.2: Grooming and dressing

The ADLs that may fall under the umbrella term of grooming include: combing and styling hair; oral care; shaving; blowing one's nose; putting on make-up; and fingernail and toenail care including clipping and varnishing. To date, no research has investigated these grooming ADLs in relation to people with dementia. Although people with dementia are likely to eventually become impaired in relation to these tasks (Beck et al., 1993), the research evidence as to how the person with dementia's cognitive and physical functional limitations affects such tasks is sparse. Such activities are likely to be affected by the person with dementia's poor planning and sequencing, dexterity, hand-eye co-ordination, and flexibility. There has been some focus in the literature on the difficulties people with dementia have with dental hygiene. However, research has once again focused less on explaining the cognitive, physical, and environmental causes of task disability, but rather only addressed the reduction of challenging behaviours displayed by people with dementia when receiving dental care (Jablonski et al., 2011). Such behaviours include clamping the mouth together, turning the head away, hitting, and kicking (Chalmers et al., 1996). It has been suggested that many of these behaviours are triggered by the carer attempting to conduct the activity improperly (Coleman and Watson, 2006). For example, a carer may attempt to insert the toothbrush into the person's mouth without warning them or determining whether he or she would like to attempt to brush his or her own teeth. Good oral hygiene is important to reduce potential pain and encourage the intake of food and fluid. There is a need for more research on the difficulties experienced by people with dementia when performing grooming tasks.

Dressing has received greater attention in the dementia literature. Dressing requires both cognitive and physical capabilities to complete. Problems with cognitive processes of perception, attention, initiation, memory, and judgment can all lead to difficulties dressing when selecting clothes, remembering the correct dressing order, and putting on items (Beck, 1988, Feyereisen, 1999). Beck (1988) and Feyereisen (1999) also indicated that operating fastenings can become difficult for people with dementia, but did not specify whether fastening errors were due to cognitive or physical functional limitations. Mann et al. (2005) explored dressing difficulty in interviews with 1,101 non-cognitively impaired but frail older adults. The authors demonstrated there were many intricate

aspects of dressing activity, such as whether people experienced problems dressing their upper or lower extremities, or struggled with buttons but not zips. Being aware that people with dementia have 'difficulty dressing' is not sufficient for developing appropriate care interventions and for providing relevant ATs. More detailed research is required on grooming and dressing ADLs performed by people with dementia.

3.4.3: Toileting and continence

More research attention has been given to toileting and continence activities among people with dementia. Toileting is a person's ability to evacuate their bladder and bowels in a socially-accepted location: the toilet. This includes correct use of the toilet. Continence is a person's ability to control their bladder and bowels, again until they can evacuate in an appropriate place. Incontinence refers both to inability to control bodily functions resulting in involuntary leakage of urine or faeces (Hägglund, 2010), or evacuation in an incorrect location such as in the person's clothes (International Longevity Centre-UK, 2013). Also of concern for older adults, including those with dementia, is constipation. Constipation may be defined as a reduction in the frequency of bowel movements accompanied by symptoms such as hard ('impacted') stools, straining, or feeling that the bowels are not completely evacuated (International Longevity Centre-UK, 2013, Talley et al., 2003).

Poor toileting behaviours, incontinence, and constipation may be affected by cognitive and physical functional limitations as well as the person's environment. Cognitive impairments can produce deficits in the ability to: sense the need to void the bladder or bowels (Barrett, 1993, Bravo, 2004); plan the actions needed to get to a toilet; locate and understand how to use the toilet (Coppola et al., 2002); evacuate in an appropriate place; and for males to locate and direct the penis correctly (Drennan et al., 2011). Physical causes include immobility (Bignell and Getliffe, 2001, Duffy, 1987) and pain or other consequences of co-morbidities such as UTIs, prostate issues, or medication (Alzheimer's Society, 2013e, Ouslander, 2000). Furthermore, difficulties with other ADLs can affect toileting; for example, problems undressing can contribute to soiling accidents (Leslie, 2005), and poor eating habits such as a decrease in fluid or fibre in the person's diet can cause constipation. Again, research suggests that the design of the person's environment contributes to all of these difficulties (Leslie, 2005). For example, a closed bathroom door blocked the toilet from a person with dementia's view, thus causing him or her to evacuate in an inappropriate location because they forgot the toilet was located beyond the door.

Managing toileting and continence is important because urine and faeces are caustic to skin and cause skin breaks and ulcers, especially common among people immobile in later-life (Watson, 2003). Skin integrity may also be compromised if cognitive and physical impairments prevent a person's ability to interpret numbness when in one position for a long time, or to perform the small movements needed to prevent pressure sores (Watson, 2003). The pain and potential infections from such outcomes can be life-threatening. Skin breakdown caused by immobility and incontinence affects well-being, and increases likelihood of institutionalisation (O'Donnell et al., 1992).

Incontinence is perceived as a stigmatising and embarrassing condition because it suggests that the person lacks control over their body. Being incontinent may lead a person to withdraw from social activity, thus trapping them in their home (Twigg, 2000). It may also damage the relationship between the person and their informal carer, as it signals further reliance (Brittain and Shaw, 2007). Drennan et al. (2011) interviewed 32 informal carers to investigate their strategies for managing incontinence. At first, carers were resistant to contacting formal services, to preserve their relative's sense of dignity. Their initial strategies typically consisted of verbal prompts to go to the toilet, but this sometimes led to arguments. The carers then tried physically helping their relative with dementia go to the toilet, which resulted in embarrassment for both parties (Drennan et al., 2011).

3.4.4: Feeding and eating

Research has also given much attention to the feeding and eating activities of people with dementia. Feeding is the specific ability to get food into the mouth. Eating also includes a person's ability to: detect the presence of food, move it from plate to mouth (feeding), chew, and swallow (Chang and Roberts, 2008, Siebens et al., 1986). Cognitively, as people age their brains experience stronger satiety signals than before, leading to a reduction in appetite (Donini et al., 2003). Eating also becomes impaired in people with dementia because they may forget that they should eat, become unable to prepare food (an IADL), become distracted when eating, and be unable to co-ordinate cutlery (Amella et al., 2008, Barratt, 2004, Griffin, 1995). They may also display resistive behaviours when being assisted to eat such as clamping the lips together, turning the head, and spitting out food (Amella, 2002, Aselage and Amella, 2010).

Physically, the ageing process produces changes in the mouth that impair chewing such as tooth loss, shrinking gums, reduced saliva, and decreased jaw strength (Barratt, 2004). Pain from tooth loss and shifting teeth can negatively impact on eating behaviour (Chai et al., 2006). Feeding and eating difficulties for people with physical impairments of the arms and hands can include:

maintaining stability of a plate or bowl; cutting up food and getting it onto cutlery from the plate; and poor grip of cutlery and mugs. Sensory impairments may lead to burns. More dangerous are the possibilities of dysphagia, which is the inability to effectively and safely swallow (Hargreaves, 2008), and choking on aspirated food (Finucane et al., 1999). Homer et al. (1994) estimated there to be some level of dysphagia in 45% of people with dementia living in care homes. Swallowing requires input from neurological functions, but nerve damage from dementia can affect the detection of food in the mouth, and related motor damage affects airway closure (Easterling and Robbins, 2008). Aspirated food particles that fall into the trachea can become lodged in the lungs and cause irritation and localized swelling; the swelling encourages pneumonia and other pulmonary infections (Griffin, 1995, Langmore et al., 2002). A pureed diet and thickened fluids may prevent these conditions, but lack physical appeal (Griffin, 1995).

The way others, such as carers, interpret the eating behaviour of a person with dementia is also important. Thus, once again the environment is critical. For example, a person looking at their food but not eating may be perceived by others as not hungry and the food taken away; in actual fact the person may be agitated by noise in their environment or unable to detect the food in front of them (Griffin, 1995). Difficulties with eating could lead the person to become malnourished (Donini et al., 2003, Berkhout et al., 1998, Dornaer, 2005). Indeed, historically some care home residents with dementia had dangerously low Body Mass Index (BMI) (ratio of their weight to their height) (Barratt, 2004). Other consequences of reduced food intake include dehydration, skin breakdown, hypothermia, osteoporosis, low immunity, delayed healing, and premature mortality (Amella et al., 2008, Aselage, 2010, Department of Health, 1992, Durnbaugh et al., 1996). One recommendation for people with dementia at risk of these conditions is a change to a high calorie diet, for example using full-fat milk and extra sugar to enhance flavours to encourage eating (Barratt, 2004). This is also because as a person ages their sense of sweet tastes become impaired to a lesser degree than sour, salt, and bitter tastes (Donini et al., 2003). Highly spicy or sweet foods can also be preferred due to a diminished sense of smell (Easterling and Robbins, 2008). The prevention of malnutrition and dehydration as a consequence of feeding and eating disability are particularly important, because they in turn can lead to: further impairments at cellular level; more functional limitations at the whole body system; and consequently further disability (Barberger-Gateau et al., 2002).

3.4.5: Previous research ignores specific task difficulties within ADLs

It became apparent when analysing the evidence presented above that it remains unclear which specific tasks that form each ADL are affected among people with dementia, and why. For example,

Gillioz et al. (2009), in their study of the pattern of ADL decline among people with dementia, listed 'personal hygiene' as an ADL. Yet this broad category can include a range of activities such as hand-washing, face-washing, showering, bathing, brushing teeth, blowing one's nose, cutting nails, and combing hair. Furthermore, within each of these activities there are specific tasks that must each be performed for successful completion. For example, to brush his or her hair a person must: locate the brush, pick it up, lift it to the head, comb it through the hair, understand when the task is finished, and return the brush to its place. Hair-brushing thus requires both cognitive and physical functions: for example, understanding the hair needs combing and range-of-motion in the shoulder to pick up the brush. These physical and cognitive actions are different from those required to shower, an ADL that could also come under the umbrella term of 'personal hygiene'. The person may be able to perform some of these cognitive and physical tasks alone, but require assistance with others. Similarly, an individual may be able to perform one 'personal hygiene' activity wholly alone, but still require assistance with others.

Therefore, research articles that state that 'people with dementia have problems with personal hygiene' lack specificity with respect to ADL task, and provide a limited evidence base for making recommendations for appropriate human assistance (Vellas et al., 2005), relevant AT use, and formulating suitable policies. Thus, in this study, informal and formal carers' perceptions of the cognitive, physical, and environmental specificities of task difficulty within ADL performance for a person with dementia they knew were explored. Then, accounts of how humans and ATs provided assistance with the specific tasks within ADLs were captured; these are two coping strategies that may alleviate ADL disability, and were introduced in a modified version of the Nagi scheme presented below.

3.5: Moderating factors of the disablement process: carers and technologies

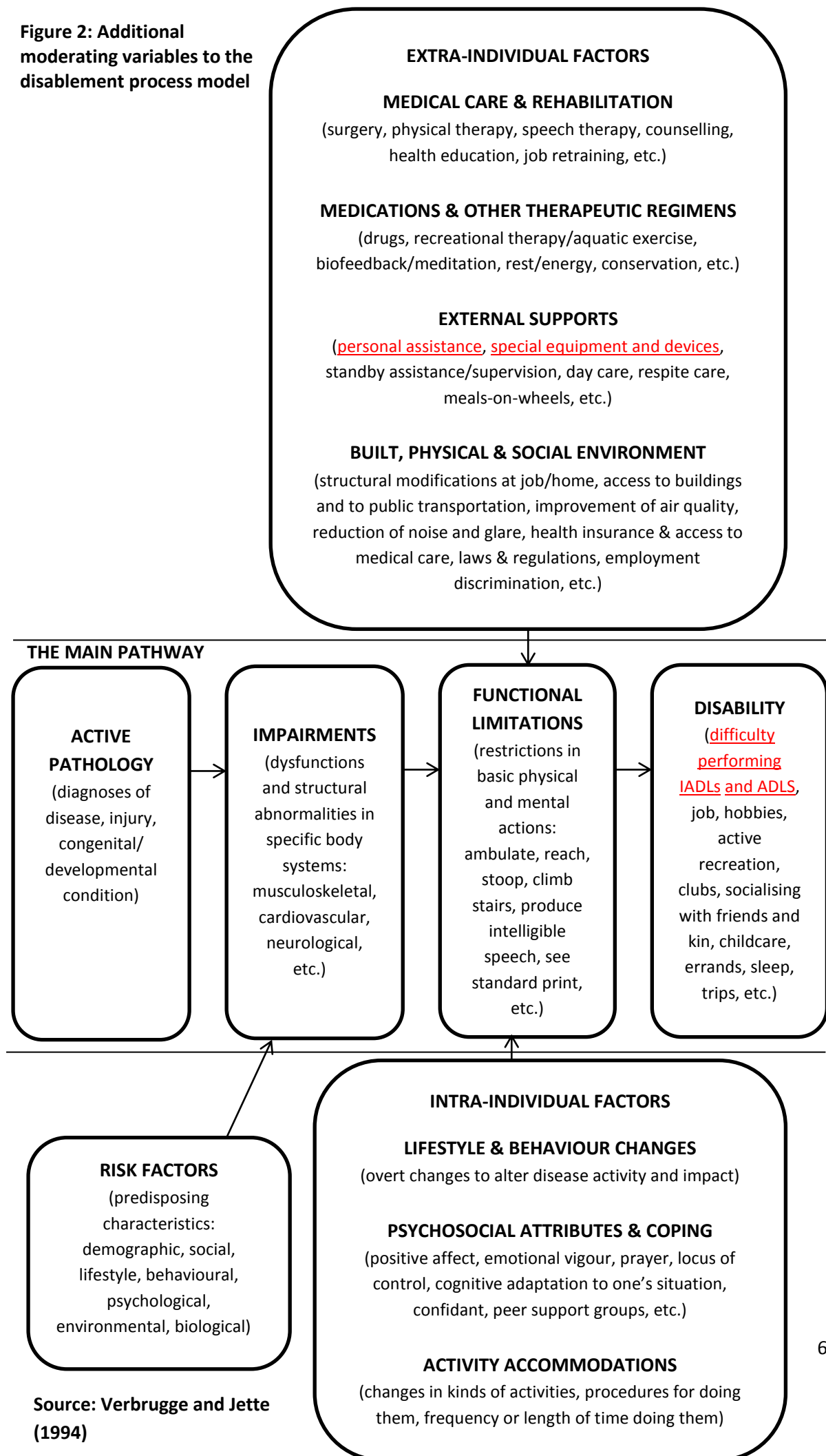
In this section, amendments that were made to the disablement process model are introduced. These amendments describe the moderating factors that may affect the rate at which the disablement process occurs within a person. Two of these factors, human carers and ATs, form the focus of this thesis.

Figure 2 below illustrates the modified disablement process model developed by Verbrugge and Jette (1994). They recognised that the pathway from disease pathology to ADL disability does not occur in a social vacuum, and acknowledged the contribution of biological, behavioural,

psychological, social, and environmental factors to the complexities of disablement. Verbrugge and Jette (1994) grouped these factors into: risk, extra-individual, and intra-individual components. It can be seen in Figure 2 that these components moderate the severity and speed of the disablement pathway. Risk factors include biological and behavioural characteristics; therefore the presence of chronic conditions or harmful behaviours in addition to dementia may contribute to accelerated disablement. For example, the cognitive impairment of decreased attention can occur as a symptom of dementia, of depression, or due to vitamin deficiency caused by poor eating behaviour (Alzheimer's Society, 2013a, Dierckx et al., 2007). Thus, when dementia, depression, and vitamin deficiency occur as co-morbidities (Donini et al., 2003), impaired attention can be experienced more acutely or quickly than each condition alone, according to the model (Verbrugge and Jette, 1994). Further, when co-morbidities are treated, some eating disability among people with dementia can be reduced (Slaughter et al., 2011). This further illustrates that, despite presented as a pathway, the components of the model do not necessarily occur in rigid linear fashion but are somewhat flexible and inter-woven.

The modified disablement process model also demonstrates how intra-individual and extra-individual factors can affect disability (Verbrugge and Jette, 1994). These factors either increase the person's ability to perform the necessary actions, or reduce the demands of the activity on the person. Intra-individual factors, shown at the bottom of Figure 2, are those internal to the person and include their psychological attributes and behaviours. For example, a good diet and smoking cessation may help to delay further cognitive and physical functional limitations in a person with vascular dementia. A person's exercise behaviour may slow the disablement process by increasing or retaining their muscle strength and flexibility (reducing physical impairments) and preserving mobility and balance (preventing functional limitations). This then reduces the influence of a potentially disabling environment, such as an uneven pavement surface.

Figure 2: Additional moderating variables to the disablement process model



Source: Verbrugge and Jette (1994)

Extra-individual factors, shown at the top of Figure 2, refer to environmental factors (Jette, 2006). These include, for example, the introduction of medication to delay progression of dementia symptoms, and environmental modifications to ease the demand of the task. Environmental modifications are closely related to ATs and can reduce ADL disability (Fox, 1995, Gitlin et al., 1999). Examples include the installation of ramps and grab-rails in a person's house, or changing the colour of objects to aid visual contrast. Also shown under the 'external supports' section of the extra-individual factors, highlighted in Figure 2, are the presence of human and technological supports. These two types of assistance are the main focus of this study. Human (carers) and technological (ATs) assistance with daily activities are defined as 'social care', as ADL disability is considered a non-medical problem (Age UK, 2012b) even if the difficulty is partly determined by a physical health condition like dementia. Care considered clinical or medical in nature falls under healthcare policy in England (Comas-Herrera et al., 2007). The exception among ADLs is incontinence, which is considered a healthcare issue so advice and related ATs are provided by District Nursing services. Boundaries are also blurred when considering NHS-funded Occupational Therapy services; the aim of which are to improve functioning and ultimately ADL performance, and may include the provision of ATs. Nevertheless, the disablement process model is useful for understanding and planning dementia care for ADL disability, as it reflects and supports the person-centred approach to health and social care services which was introduced in Chapter 2. Three domains within which the two conceptually overlap, and one way in which they do not, are presented below.

3.6: Conceptual overlap between the disablement process model and the person-centred care approach

The overlap between the disablement process model and the person-centred approach to care occurs in three domains. First, they both acknowledge the importance of bodily and environmental factors in creating or alleviating disability. Second, they both champion the perspective of the individual and their participation in decision-making. Third, they both appreciate the importance of communication; in the disablement process model the communication between the body and the environment, and in person-centred care the importance of appropriate carer communication. However, the two do not overlap in one area; person-centred care posits that the focus should be only on the person's abilities whereas the disablement process model cannot be used to inform appropriate care without acknowledging the difficulties and disabilities they experience. These four points are discussed below.

The first conceptual overlap is that both highlight the importance of the environment in creating and identifying disability (disablement process model) and recognising and alleviating it (person-centred approach to dementia care). That is, both do not deny that a pathological bodily state serves as the root cause of ADL disability (Innes, 2009, Kitwood, 1997a, Verbrugge and Jette, 1994). Yet, both highlight the importance of understanding the person's environment, social world, psychological characteristics, and life course as shaping the disability experienced (Kitwood, 1997c, Verbrugge and Jette, 1994). Placing as much importance on the environment as on dementia symptoms represents a holistic view which is important for providing suitable ADL assistance (Innes and Manthorpe, 2012, Wilberforce et al., 2016b). For example, the disablement process model recognises that the social environment created by carers' negative attitudes may contribute to the disability experienced; person-centred care could tackle these attitudes to produce a nurturing and supportive environment (Kitwood, 1997a). This would ultimately aim to enhance cognitive and physical functioning and reduce disability (Manthorpe and Samsi, 2016).

The second overlap between concepts within the disablement process model and person-centred care relates to ensuring that the perspectives of the individual are taken into account. Nagi (1991) stressed that disability is relative, which includes how it is perceived by the individual experiencing functional difficulties. That is, whether the person themselves feels that he or she is disabled when performing the socially-defined ADLs. This reflects the person-centred approach to dementia care, which champions the person's unique interpretation and experience of illness or disability (Kitwood, 1997a). As the person's subjective experience is taken as reality (Brooker, 2003), the person with dementia should be engaged in decision-making for care plans as much as possible (Wilberforce et al., 2016a). This can result in tailored and flexible care services which are responsive to the person's preferences as well as their needs (Wilberforce et al., 2016a, Wilberforce et al., 2016b). Furthermore, the extra-individual factors (carers and ATs) noted in the disablement process model may actually exacerbate difficulties if they are applied in a non-person-centred way that goes against the person with dementia's wishes (Barberger-Gateau et al., 2002).

The third conceptual overlap between the disablement process model and person-centred approach to dementia care concerns the role of communication. In the disablement process model, Nagi (1991) stressed that the 'problem' of disability lies in the communication between the body with dementia and its surroundings. Similarly, Kitwood (1995) suggested that rather than seeing the person with dementia as the 'problem' and carers as without problems, disability is interpersonal

and occurs due to lack of communication between them (Brooker, 2003). In both approaches, an improvement in communication may improve the lives of people with dementia and carers.

One conceptual domain within which the disablement process model and person-centred care approach may not overlap is their focus on disabilities and abilities respectively. That is, person-centred care should focus on the person's abilities rather than what has been lost because of the dementia (Kitwood, 1997a). This approach preserves the identity of the individual. However, on a practical basis, creating an appropriate care plan necessitates open acknowledgement of the person's disabilities and difficulties. Thus, the disablement process model can be useful. Without identifying disabilities, there is a risk of unsuitable ADL assistance through either over-assistance or under-assistance. As was described in the introduction to this chapter, human assistance from carers is presented below and technological assistance is given attention in Chapter 4.

3.7: Human assistance with ADLs: informal carers

In this and the following section, the human assistance that can be provided to people with dementia for ADLs by carers is outlined. There are two types of carers: 'informal' (usually an unpaid and untrained family member) and 'formal' (paid, trained and whose assistance to the care-recipient is regulated by a written care plan and under virtue of a contract) (Jarrott et al., 2005, UK Parliament, 2014). The barriers that people with dementia and their family members may face when accessing formal social care services are then discussed.

Once a person is no longer able to perform ADLs alone, they are viewed by others as in need of (usually human) assistance (Molin et al., 2007). Humans assist people with dementia to conduct ADLs in multiple ways. They provide supervision and assistance for ADLs via: verbal prompting (reminding or advising the person what to do next), physical guidance (drawing attention to a part of the person's body), stimulus control (altering the environment to be more enabling), and gesturing and modelling actions (imitation of the intended action) (Beck et al., 1993). To illustrate, a carer may assist a person with dementia to brush their teeth using: verbal instructions to pick up their toothbrush; physical assistance by squeezing the toothpaste on to the brush; changing the toothbrush to a more eye-catching location to enhance visibility; or gesturing by miming a brushing action so the person with dementia can remember what to do or copy their movements. Using these techniques, human carers can compensate for the functional limitations and disabling environment of the care-recipient.

For all older adults who require assistance, Cantor's (1975) hierarchical-compensatory model suggests that the closest individual to the person in need is likely to volunteer their time to help the individual complete ADLs. They then become the 'informal carer' (Kingston et al., 2012). Indeed for the two-thirds of all people with dementia who live in the community, it has been estimated that 53% receive help from informal carers alone and only 34% from a combination of informal and formal carers (Knapp and Prince, 2007). As in the general frail older population, research has demonstrated that informal carers of people with dementia are either the spouse or adult child of the care-recipient, and usually the female members of the family (Hirst, 2005, Ferrara et al., 2008). Further, research evidence has found most informal carers of older adults are aged 45-64 years old, indicating that adult children are often fulfilling these roles (Pickard, 2003).

An informal carer may need to dedicate more hours than are in a typical working day to ensure their relative's well-being (Wimo et al., 2002). Many of the ADLs are clustered around morning or evening routines, for example: transferring into or out of bed, toileting, washing or bathing, dental care, hair grooming, and dressing. Other mealtimes and toileting needs are interspersed throughout the day. Assistance with mobility may be required constantly. Additionally, informal carers of people with dementia can spend up to 50% of the day on surveillance to monitor their safety (Wimo et al., 2002). Under such circumstances, full-time employment for informal carers becomes difficult (Ferrara et al., 2008). In particular, people with dementia may need between five and 20 years of care and the role can be physically and emotionally demanding for informal carers, leading to stress and ill-health (Sarafino, 2006). It can be particularly stressful for informal carers of people with dementia, as feedback from care-recipients may be sparse (Lévesque et al., 1999, Stuart-Hamilton, 2006). The physical, mental, emotional, and time demands on the informal carer may contribute to a decision to move the person with dementia to a full-time care institution such as a care home. Furthermore, co-resident carers typically provide more hours of care than those who do not live with the care-recipient (Hirst, 2005). When a person with dementia lives alone they are more likely to go from living in the community to a care home in comparison to those who live with someone else (Brodaty et al., 2000). Who makes such a relocation decision and how this is made are discussed in Chapter 5. This type of relocation will be referred to throughout this thesis as 'institutionalisation', defined as both the process of placement in a care home and the act of residing in such a location. Prior to this however, workers from formal care services may effectively assist the care-recipient with ADLs at home, which may reduce some informal caring tasks.

3.8: Human assistance with ADLs: formal carers

As discussed in Chapter 2, formal social care services include domestic tasks such as housework and food preparation, but particularly assistance for people with dementia to perform ADLs (Raivio et al., 2007). The eligibility restrictions placed on individuals in need of assistance were also presented in Chapter 2; some may be eligible for state-funded formal support whereas others must privately purchase these services. However arrangements are made, formal carers may provide essential assistance to people with dementia who have no informal carer, or their help may complement an informal carer's work in supporting a person with dementia at home (Soldo and Manton, 1985). In addition, evidence suggests that the respite that formal services can bring to an informal carer may be enough to enable them to continue their role for a longer period of time (Gaugler et al., 2000), and may act to significantly reduce carer distress, overload, or anger (Jarrott et al., 2005).

Further, research has shown that assistance from other informal sources such as family members and friends does not reduce an informal carer's distress (Jarrott et al., 2005). This is possibly because informal carers may feel guilty when receiving help from such individuals. A trained, less emotionally-attached formal carer may be better able to cope with challenging behaviours, promote both the care-recipient's and the informal carer's sense of autonomy and enhance their sense of well-being. This may be particularly evident in the most private and sensitive of ADLs such as toileting and continence. However, research has shown that formal carers (of older adults in general) expect continued assistance from the care-recipient's family members and friends (Clough et al., 2007). More research is needed to investigate the relationship between informal and formal carers of people with dementia; for example, when and how formal services are contacted to assist with performance of ADLs, and informal and formal carers' provision and use of appropriate ATs. These will be investigated for research question 3 of this project, which concerns preferences, barriers, and facilitators for ATs.

Research evidence has suggested that waiting too long to use formal care services may mean that the care-recipient becomes too severely cognitively or physically impaired to benefit from community-based assistance (Zarit et al., 1999). The person at this point may instead require relocation to a 'residential care home' or a 'residential care with nursing home'. These will both be referred to throughout this thesis under the umbrella term of 'care home' (Alzheimer's Society, 2010, International Longevity Centre-UK, 2013). To prevent or delay institutionalisation, researchers have investigated the barriers that may deter a person with dementia or family carer from

contacting formal care services for help. These are important to understand in order to assist the exploration of research question 3 in which the relationships between families and formal services are queried as barriers or facilitators for AT use.

3.8.1: Perceived barriers to formal care services

Brodaty et al. (2005) conducted a comprehensive analysis of four barriers to formal care service use for people with dementia and their family carers. These were: carers' perceived lack of need for a formal care service; their lack of awareness of available services; their perceptions of poor quality services; and other service characteristics such as financial cost and complexity of negotiation. Other research on the barriers to service use identified demographic characteristics of the groups most likely to underuse formal services (Robinson et al., 2005a, Robinson et al., 2005b). Each of these five potential barriers to formal care services are discussed in turn below.

Informal carers' perceived lack of a need for formal carers was a main reason for non-use of such services (Brodaty et al., 2005). Carers who cited this reason were often managing on their own, either because they provided care to someone they perceived to require a low level of assistance, or they received support from other family members. A perceived lack of need is an understandable explanation for non-use of services (Hong et al., 2011). Alternatively, it may reflect a lack of knowledge about their relative with dementia's level of need and how formal care services could provide effective assistance.

A second barrier to service use by people with dementia and their families was a lack of awareness of what was available, including ATs (Brodaty et al., 2005, Morgan et al., 2002, Wright et al., 2005). More specifically, important distinctions should be made between awareness of services and knowledge of what they could actually provide (Krout, 1983). That is, a carer may have heard of adult social services but not be aware of the extent to which they could be helped by social workers; therefore they would be unlikely to contact them. Yet, other research demonstrated that awareness of services may not be as salient a barrier to service-use than was previously thought (McCallion et al., 2004). McCallion and colleagues (2004) demonstrated that only one-third of informal carers who were offered information on local health and community services agreed to receive it. This suggests that the first barrier of lack of perceived need could indeed be most significant.

A third barrier for people with dementia and their carers to using in-home care services was perceptions of poor services (Brodaty et al., 2005). Understanding public attitudes about the quality

of services is important. Graessel et al. (2011) demonstrated that punctuality of in-home formal carers was more important to family members than the workers' empathy or communication skills. Other research on formal care services highlighted families' concerns about the lack of training in caring for a person with dementia, poor-quality care, and unethical behaviour including neglect, theft, and exploitation (Estes and Swan, 1992). In this thesis, family members' relationships with formal care services and their employees was investigated, particularly with respect to using ATs for ADLs with the person with dementia.

Service characteristics, particularly complexity and affordability, were identified as a fourth main barrier (Brodaty et al., 2005). First, many informal carers believed that managing and negotiating one's way through the complex social care system was overwhelming. It has even been suggested that some carers or people with dementia may be suspicious that services are designed to prevent them from getting help (Clough et al., 2007). Others may have lost confidence that services can help them if they have experienced previous failed attempts (Clough et al., 2007, Wright et al., 2005). Second, finances were an obstacle to service use. Indeed, Hong et al. (2011) found affordability and insurance status, that is, Medicaid or private insurance, to be consistent barriers to formal service use for older USA (United States of America) citizens. The relevant UK social care policies that determine the circumstances under which a person can receive funded social care assistance were presented in Chapter 2. Although many people living in the community can access funded care, family carers may be unaware of their eligibility.

A fifth potential barrier to accessing formal services concerns the demographic characteristics of the caring dyad. Research has shown that spousal carers are less likely to use formal services (Robinson et al., 2005a). Spouses may feel stress relating to formal service use (Sussman and Regehr, 2009), as they may believe that they alone should care for their spouse. Informal carers may not access formal care services if they perceive that they should only be contacted if they cannot 'do their own job' caring for their relative (Pickard et al., 2000). Evidence has also suggested that care-recipients looked after by spouses are significantly less likely to be institutionalised (Estes and Swan, 1992, Freedman, 1996). For spousal carers, use of services may be an admission of need for help and result in a sense of betrayal and guilt. This suggests that spouses may require more emotional support because of this guilt, compared to other types of informal carers such as adult offspring who may require more assistance with the co-ordination of dementia care (Peeters et al., 2010).

3.9: Chapter 3 summary

In this chapter, the disablement process model was introduced in order to assist understanding of how dementia may lead to poor performance of ADLs. According to the model, cognitive and physical impairments which occur in a person with dementia lead to functional limitations, such as immobility, and poor sequencing of actions. These functional limitations then interact with the environment to affect performance of socially-defined activities considered crucial for self-care, known as ADLs. Poor performance of ADLs can lead to a label of disability. To date, there is little research evidence detailing how ADLs are affected among people with dementia; which specific actions are particularly difficult, and why.

An extension of the disablement process model was also introduced, to demonstrate factors which may moderate the effect of functional limitations and the environment on ADL performance. This thesis focuses on two of the factors, human and technological assistance, known as 'social care'. Humans, either informal or formal carers, verbally and physically assist people with dementia to conduct ADLs. Yet, people with dementia and their families experience barriers when accessing formal care services. An alternative management strategy to coping with ADL disability among people with dementia may be the introduction of ATs. Appropriate ATs may alleviate the need for human assistance, reduce time and task pressure on informal carers, and enhance the person with dementia's sense of independence (Boger et al., 2006, Cahill et al., 2007). The contribution of ATs to dementia care is introduced in the following chapter.

Chapter 4: Assistive Technologies to help people with dementia perform ADLs

The latter sections of Chapter 3 demonstrated how carers may provide verbal and physical assistance for ADLs to people with dementia. In this chapter, the ATs that people with dementia and their carers may alternatively, or additionally, use are presented. First, the presentation of reviewed literature on the ATs being used by people with dementia is discussed. The discussion then turns to ways that ATs may help people perform activities. Typically, ATs either modify the environment or target the physical and cognitive functional limitations of the ADL-disabled person. This is followed by the ATs used in general daily life, and then devices specifically designed for assisting ADLs.

The presentation of the reviewed literature on preferences, barriers, and facilitators for ATs is then discussed. The chapter content continues with a critical analysis of the empirical research that has investigated how ATs are actually used, with a particular focus on whether ATs can substitute for, or merely supplement, the assistance of human carers. Much research concludes that it is important for carers to remain involved in ADL assistance even when ATs are used by cognitively-impaired populations. The literature reviewed in this study uncovered several key knowledge gaps. These are: which ATs for ADLs are actually used by or with people with dementia in the community; how ATs for ADLs become used by people with dementia and their carers; where such devices are obtained; and how use of these technologies among this group is maintained. Furthermore, little work has captured informal and formal carers' perceptions of the role that ATs can have in dementia care for ADLs. All of these knowledge gaps are discussed in this chapter.

In the penultimate chapter section, the ethical issues raised by potential technology-users, informal and formal carers, and other health and social care professionals are explored. Recommendations for appropriate design of ATs to be used by and with people with dementia follow.

4.1: Presentation of reviewed literature for topic 2

Sections 4.2 and 4.3 of Chapter 4 cover the thematic analysis from the scoping review of literature for the second topic: the types of ATs used by people with dementia and their informal and formal carers in community settings. First, section 4.2 presents literature themed on how ATs are thought to support the performance of ADLs. Links back to the modified disablement process model introduced in Chapter 3 are made. Papers for this short section were not required to be dementia-specific as long as the focus concerned ATs for ADLs and not other activities.

The main discussion of this second topic is presented in section 4.3; themed to introduce the reader to different ATs that may assist people with dementia in general daily life and with the performance of the individual ADLs under investigation. Referenced papers in this section included grey literature, because relevant charity factsheets and reports included lists of ATs that could be accessed from social care services in the UK. These sorts of lists were not typically provided in peer-reviewed academic papers. Given that this section first concerned non-dementia specific ATs and home modifications for mobility and non-ADL activity, some references were not related to those with dementia or to ADL performance. This section had a spread of references from different countries, as technology researchers from Europe and Canada had written relevant dementia articles or conceptual papers. As well as listing ATs for ADLs in this section, any relevant critical work on effectiveness of ATs was referenced where suitable. For example, in sub-section 4.3.1 on bathing and washing ATs, Gill et al. (2007) were referenced as their findings suggested that use of many bathing ATs did not reduce the likelihood of developing further disability when bathing. Although the research by Gill et al. (2007) was conducted in the USA and with non-cognitively impaired but physically-frail older adults, it was included to challenge the policy assumption that ATs can prevent or reduce disability. This set the scene for the discussion on the benefits of using ATs for ADL performance in sub-section 4.3.5.

Overall, the key knowledge gap resulting from the thematic analysis conducted on reviewed literature for the second topic was that no research was identified which had investigated the ATs used by people with dementia and their carers in community-settings. Research that had been conducted was organised around three themes: ATs for ADLs but not for those with dementia; the difficulties people with dementia had when performing ADLs but which ignored ATs; or, for those that investigated dementia, ADLs, and ATs, used measurements of device use and satisfaction deemed not useful. These themes occurred from the overall impressions from the scoping review, but it is again acknowledged that many references were from the USA. The three themes are presented later in Chapter 4 in section 4.6, as they were grouped with the knowledge gaps from topic 3. It is important to know the types of ATs that people with their dementia and their carers are using in England; thus, research question 2 and the design of this study to explore AT use were finalised. This included understanding statistical associations of AT use in a nationally-representative sample (see Chapter 6), and qualitatively exploring retrospective and current AT use in community and care home locations (see Chapters 7, 8, and 9).

4.2: How ATs may assist the performance of ADLs

The disablement process model introduced in Chapter 3 outlined how ADL disability can occur as a result of both bodily functional limitations and an unsupportive environment (Nagi, 1965).

Verbrugge and Jette's (1994) modified disablement process model also demonstrated that extra-individual factors such as special equipment and devices (ATs) can target bodily functions and the environment to enhance a person's performance of ADLs. Defined in detail in Chapter 2, an AT is here considered as any technological device that helps a person to perform a task. Assistive Technologies may enhance ADL performance in three ways. First, a device may act to reduce environmental demands (Agree and Freedman, 2003); for example, taps with long lever handles are easier to operate than taps with twist tops, which require greater wrist strength and flexibility. Second, a device may expand the individual's capacity (Agree and Freedman, 2003); for example, angled cutlery does not require the user to rotate the wrist when eating. Third, ATs can replace a step in a sequence thereby reducing task complexity (Gitlin et al., 2002); for example, elasticated shoelaces eliminate the need for a person to constantly tie and re-tie them.

Almost 75% of physically disabled older people use some kind of AT (Norburn et al., 1995). In particular, ADLs have been shown to be more responsive to AT use than the complex IADLs (Agree et al., 2005). There is a broad market of ATs for ADLs ranging from basic devices such as a cup with an extra handle, to 'smart' or 'intelligent' technologies that monitor people in their home. The ATs that may be used by all persons, including those with dementia, and their carers in general daily life are set out below. This is followed by a discussion of devices which may be used to assist with the performance of each of the ADLs explored in this research.

4.3: Assistive Technologies that may be used in daily life

The sub-sections of 4.3 present the ATs used for each ADL under investigation in this thesis: bathing and washing; grooming and dressing; toileting and continence; and feeding and eating. First, some discussion is presented on other ATs that may be used by people with dementia and their carers to support the cognitive, physical, and social processes needed to manage other aspects of the daily life of the person with dementia whom they were discussing. They are listed here because some carer-participants in this research indicated that such devices were used to manage the memory, orientation, mobility, and transferring difficulties of those with dementia. Memory devices include the use of calendars, medication reminder boxes, or movement-activated sensors which trigger a recorded message. Other sensors include nightlights that are triggered when people pass them in a

dark environment, so are useful for people with dementia who get up in the night but forget to use the light switch. Orientation devices include room signs for way-finding and large-faced analogue or digital clocks that display the day and whether it is morning, afternoon, or night-time. Mobility and transferring ATs help with physical safety. They include walking sticks, walking frames, manual and electric wheelchairs, water-chairs, stand-aid-hoists, transfer boards or slide-sheets, armchair elevators, powered riser-recliner chairs, and nursing beds that elevate the head or feet (Age UK, 2012c). It is important to be aware of these ATs because, although they are not specifically designed to help a person conduct specific ADLs, they can indirectly provide assistance with these types of activities. For example, a reminder memo-board and stool at the bathroom sink may both help a person with dementia to wash in the morning, thus promoting the performance of washing ADL. All ATs can be further classified into dementia-specific and non-dementia-specific types of devices.

Non-dementia-specific ATs are those which are used in social care for people with physical impairments who may be either cognitively well or unwell (Nochajski et al., 1996); for example grab bars and bath seats. Many such types of ATs are able to accommodate the design of a person's home. Home modifications can help with the performance of ADLs and promote living at home (van Hoof et al., 2010). To illustrate, corridor handrails could enable a person to get to the bathroom more quickly, thus aiding continence management. In this way, an enabling environment interacts with functional limitations to enhance ADL performance (Wahl et al., 2009). Non-dementia-specific ATs focus on the physical aspects of performing the activity, or living safely. The most commonly used ATs by older adults in general are mobility-related such as canes, bath rails, and wheelchairs (Agree et al., 2005).

Yet, some ATs are inappropriate for people with cognitive impairments (Sixsmith et al., 2007, van Hoof et al., 2010). For example, devices which necessitate user feedback, such as a button to be pressed to begin or finish an action, may be impractical for people with dementia if they cannot remember what to do. Requiring the carer to provide this feedback adds to their workload (Boger et al., 2006, Mihailidis et al., 2008). Dementia-specific, or 'dementia-friendly', ATs for use in daily life support particular cognitive impairments, such as poor memory and difficulty planning sequences (Pollack, 2005). Some dementia-specific ATs are merely brightly-coloured versions of technologies that non-cognitively impaired people use, such as a red toilet seat instead of a white one, to provide a greater contrast with the surroundings. Other ATs, such as room way-finding signs, compensate for memory loss and disorientation (Passini et al., 2000). These 'cognitive orthotics' (Horgas and Abowd, 2004) address memory impairments through reminders and alarms to prompt the person to perform

an ADL. Tracking technologies for people who get lost while outside their house can contribute both to the care-recipient's and informal carer's feelings of safety (Pollack, 2005). Computers can not only monitor people with dementia within and outside their home (Brummel-Smith and Dangiolo, 2009), but prompt them through tasks. This type of device compensates for deficits in executive functioning (Lubinski and Orange, 1991), and reduces a need for constant carer presence. As such, dementia-specific ATs can produce safe environments within which people with dementia can live well.

People who live alone or have high needs may additionally use telecare ATs to enhance feelings of safety. Telecare technologies connect directly to a call centre when the user is in need. For example, a person may have an alarm in the form of a pendant necklace or pull-cord system on their wall. When they are in need of help, they operate the alarm to connect to a warden or call centre employee. Again, people with dementia may be unable to remember to press the alarm button in an emergency. Therefore 'smart' versions of telecare alarms can independently detect falls and automatically alert staff. These sensors can also raise alarms, such as when a person has not got into or out of bed by a designated time, or has not returned to their home by a set time (Age UK, 2013a). It is noted here that there are other types of telecommunications called 'telehealth' or 'telemedicine', whereby devices transmit data on health, healthcare, and pharmacology (Loh et al., 2005), such as daily monitoring of blood glucose. These devices were not the focus of this study, which concerned human and technological assistance (social care) for ADLs, and not healthcare or safety needs per se of people with dementia. The ATs that exist for each ADL type are listed below.

4.3.1: Bathing and washing ATs

Difficulty bathing may be partly caused by the home environment; for example a high bath may be difficult for a person with poor mobility to step into (Clough et al., 2007). A bench to facilitate transfers to and from the bath, or devices which reduce environmental risks (such as non-slip flooring, abrasive strips, or grab bars to reduce falls) may lead to a reduced need for human care (Alzheimer's Society, 2013g, Naik and Gill, 2005). Certain types of technologies are inappropriate in such private settings; video surveillance in a bathroom is largely considered to be unacceptable, so a technology that monitors activity by capturing sounds of showering, urination, washing hands, and brushing teeth has been in development (Chen et al., 2005, Vacher et al., 2013). This type of technology still elicits privacy concerns, however (Bossen et al., 2015).

Other available bath aids include shower seats, tub stools, long-handled brushes, non-skid mats, thermostat taps with long handles, and special bath and sink plug sensors that only allow the water

to reach a certain level or temperature (Age UK, 2013a, Alzheimer's Society, 2013g, Gill et al., 2007, van Hoof and Kort, 2009). For example, the Gloucester Smart House, a research and development project which converted a three-storey house into a demonstration centre for intelligent ATs, has a bath water level monitor with voice reminder function (Cash, 2003). However, these smart bath devices are not currently in public circulation or use. Ahluwalia et al. (2010) requested non-cognitively impaired but physically-frail participants to review their use of bath aids. A hand-held shower received mixed reviews, whereas handles, grab bars, and a bath chair were perceived by participants to be most beneficial. Recommendations by Cantley and Wilson (2002) for assistive bathroom devices include a toilet seat of contrasting colour to its surroundings. Yet, Gill et al. (2007) analysed longitudinal data of older adults who at baseline had no bathing disability. They showed that use of bathing ATs, apart from non-skid mats and abrasive strips, did not reduce the likelihood of developing a bathing-related disability over time (Gill et al., 2007). It may be that reliance on an AT leads to further disability if it does not help a person to improve their muscle function and strength. This may be especially so if by the time a person begins to use ATs they are already experiencing reduced functionality.

Bathing disability is associated with institutionalisation (Gill et al., 2007) and the receipt of formal care services (LaPlante et al., 2002). Community-based formal carers' time commonly consists of assisting with bathing activities (Cloutier, 1999). This means that the provision of appropriate ATs or environmental design could free up time or allow a more pleasant, holistic caring experience. For example, an environmental modification of a slit in the floor for the placement of feet while kneeling would enable carers to provide bathing assistance more comfortably (van Hoof and Kort, 2009). However, resistive or aggressive behaviour, which may be displayed by care home residents during bathing, is not only linked to their fear of an unfamiliar activity (being assisted to bathe by another person) but also to unfamiliar equipment such as bath hoists (Day et al., 2000, Namazi and Johnson, 1996).

Of the individual tasks that fall under the umbrella of washing ADL, hand-washing has received most attention from technology researchers. This is because although it requires remembering a sequence, which can be difficult for people with dementia, it is a relatively safe activity for which to test interventions (Mihailidis et al., 2008, Mihailidis et al., 2004b). For example, the COACH (Cognitive Orthosis for Assisting aCTivities in the Home) is a cognitive assistance system that monitors a person with dementia while hand-washing and offers audio or audio-video prompts to enable successful completion (Boger et al., 2006, Mihailidis et al., 2008, Mihailidis et al., 2007,

Mihailidis et al., 2004a). This smart technology uses a camera to observe states and can estimate the person's abilities, such as their dementia severity and reaction times (Lovejoy, 1991). For example, the camera can capture the position of the person's hand and the speed of water flow. When a human error is detected, the system then prompts the user with their next step (Roy et al., 2011). The technology is effective because it follows dementia-specific design guidelines that advise non-invasive, autonomous design requiring as little user-feedback as possible. However, the system has only been tested on a small sample; only six participants with moderate dementia were involved in one study (Mihailidis et al., 2008). The technology requires further and extensive testing on participants in a severe stage of dementia (Boger et al., 2006). There are plans to apply the technology to assist people with brushing their teeth, and to develop the technology so that it can respond to user comments (Carrillo et al., 2009). Although one other smart prompting technology for hand-washing exists (Peters et al., 2009), there were no published articles found in the scoping review on other types of ATs that could aid hand-washing for people with dementia. Examples include lever-headed taps or automatic soap dispensers, both of which are easily obtainable. No research was found to discuss the substitution of soap and water for alcohol-based wet wipes to aid hand-washing among people with dementia.

4.3.2: Grooming and dressing ATs

Verbal prompts for washing and grooming activities, such as brushing teeth and shaving, can sometimes be all the assistance that is needed (Wherton and Monk, 2008). Bewernitz et al. (2009) demonstrated that smart technology can prompt people with dementia through ADLs with increasing levels of complexity: drinking water, brushing teeth, and upper body dressing. Morning bathroom routine, dressing, and table-setting have also been shown to improve through computerised verbal instructions (Lancioni et al., 2009a), although these trials were based on small sample sizes. Nevertheless, research on increasing safety during bathroom (washing or grooming) activity is important as it is often seen as the most dangerous room in the home due to the risk of slips, burns, drowning, and other injuries (van Hoof et al., 2010).

Mann et al. (2005) showed that dressing ATs were most commonly used for the dressing of the lower-extremities; for example, putting on shoes and socks, and that such use can significantly contribute to reducing pain, distress, and frustration among people with dementia. Examples of non-dementia-specific dressing ATs include: long-handled shoehorns, sock and stocking aids, dressing sticks, button aids, Velcro fastenings, zipper pulls and other clothing adaptations, elastic shoelaces, reachers, and stools (Mann et al., 2005). The use of such ATs, as well as simple changes like sitting

down while dressing, can assist with ADLs (Mann et al., 2005). However, adaptive techniques, such as only wearing slippers because shoes are too difficult to put on, may contribute to social isolation.

For people with dementia, poor judgement due to impaired reasoning may result in inappropriate clothing choice and behaviours (Cahill et al., 2007). There are no smart or intelligent technologies for helping people with dementia to get dressed (Wherton and Monk, 2008). Namazi and Johnson (1992) simplified clothing choice by modifying a side of the closet that contained only the clothes the person should wear that day, and in the correct order they should be put on. However, while this may reduce confusion with clothing choice, the person with dementia would still need assistance from a carer to: choose the clothes, place them in the closet, and get dressed. If the clothes are chosen for, and not by, the person with dementia this may lead to a further loss of independence.

The choice of clothes is a way to communicate who one is, and therefore is no less important for individuals with cognitive impairment. The designers of 'functional' clothes sometimes ignore this social communication; for example a jumpsuit was designed for patients on a ward with memory problems, brain injuries, and learning difficulties to prevent them from undressing or removing their continence pad at inappropriate times (Iltanen-Tähkävuori et al., 2012). This was subsequently perceived by both family carers and the technology designers as infantilising and stigmatising (Iltanen-Tähkävuori et al., 2012). Furthermore, such a garment is ethically and morally questionable as both the prohibition of self-undressing and the necessary physical reliance on carers are methods of restriction (Iltanen-Tähkävuori et al., 2012). As such, UK policy states that care home residents with dementia must wear their own clothes (Twigg, 2010). Instead, clothes that ease dressing such as larger neck openings, larger buttons, Velcro or popper fastenings, front-open bras, and slip-on shoes are recommended (Alzheimer's Society, 2013d). However, some informal and formal carers may prefer for the care-recipient to experience difficulties undressing as sometimes people with dementia may display inappropriate sexualised behaviour, attempt to self-evacuate their bowels when constipated, or try to remove their continence pad.

4.3.3: Toileting and continence ATs

Incontinence can be shameful and embarrassing both for the person with dementia and their informal carers. Research has suggested that the introduction of relevant ATs may contribute to an 'acceptable continence' status (Brittain and Shaw, 2007). Incontinence is commonly managed with sticky-backed pads placed in the person's underwear. Only these pad-style continence ATs are funded by healthcare services. Yet, informal carers of people with dementia have suggested that

they prefer a pull-up-pants style of incontinence protection (Drennan et al., 2011), as they are breathable, leak-preventing, and easier for carers and care-recipients to use (Evans, 2007). These pull-up styles of continence technologies must be funded by the user as they are not provided by healthcare services (Fader et al., 2008). Continence pads are thought largely to support the needs, dignity, and human rights of the wearer. However, finding pads that are both effective and that have a design acceptable to the person with dementia may be difficult (Drennan et al., 2011).

Furthermore, reliance on continence pads may not necessarily be the most appropriate or cost-effective approach (Bignell and Getliffe, 2001). Alternative and preventive management recommendations include: identifying and managing co-morbidities and constipation; reducing medication if possible; acknowledging dietary concerns and timing fluid intake; bowel and bladder voiding training; pelvic-floor muscle training; wearing simple-to-open clothes; and, importantly for this study, changing the environment and providing relevant ATs for transferring, mobility, and toileting (Bravo, 2004, Duffy, 1987, Hägglund, 2010). Examples of appropriate clothing to aid continence issues include Velcro fasteners, elastic waist bands, and wearing skirts with stockings rather than tights (Duffy, 1987).

Toileting ATs include room signs and commodes (Alzheimer's Society, 2013e, Day et al., 2000). Yet, room signs may be rarely used and even offend people with dementia (Drennan et al., 2011).

Bedroom commodes may also remain unused (Drennan et al., 2011). This may be because commodes are not located in a bathroom but in the bedroom, and the person would not associate the bedroom with toileting. If a person with dementia becomes bed-bound, the best options to prevent or reduce skin irritation and infection are technological. These include: absorbent pads for underwear and bed-sheets, anal plugs to prevent the person from evacuating their bowel, and 'external collectors' such as bladder catheters, silicone continence sheaths, and faecal collectors (Bravo, 2004, Duffy, 1987). However, long-term use of bladder catheters can lead to health complications (Kohler-Ockmore and Feneley, 1996).

The study by Drennan et al. (2011) also demonstrated that some carers reported the onset of continence issues following a crisis event such as hospitalisation. That is, some people with dementia were reported by carers to have returned from a hospital stay newly incontinent. While some carers perceived professionals to misunderstand the seriousness of the situation, others reported excellent service support. Most recipients in Drennan et al.'s (2011) study found that continence ATs from formal services were restricted. The authors concluded that local provision is not sufficiently responsive to the needs of people with dementia living at home. Evans (2007) recommended that

professionals who prescribe continence aids should consider which product is more likely to: promote a sense of dignity; enable the user to be independent; and reduce the time carers spend on changing pads and clothes.

Difficulties with transfer and dressing place people with dementia at risk of soiling their clothes (Nelson and Furner, 2005). This again demonstrates how functional limitations impact on the performance of multiple ADLs. Such acknowledgement is essential for designers of effective dementia-specific technologies. For example, one intervention involved a urine sensor that alarmed when it detected wetness to improve skin integrity in people with mild to moderate AD (Lancioni et al., 2011). As well as effective absorbency, this device would need to be easy for someone with frail wrists or hands to pull down on their own. Overall, such AT has the potential for improving quality, person-centred care (Wai et al., 2008). However, Carrillo et al. (2009) described a moisture sensor prototype that sent an alert, via a wireless transmitter, to the internet 'that a diaper change is needed'. While practically useful, such language is infantilising and insulting. Adult absorbent pants should not be referred to using the same language for children's absorbent pants, as it perpetuates the misconception that people with dementia are akin to children or have 'gone backwards' in their cognitive state (Alzheimer's Society, 2013b).

Wherton and Monk (2008) identified that "toileting is the one activity where our participants, particularly the carers, would seem to prefer electro-mechanical help to human help" (p. 579). Automatic 'hands-free' toilets are available which can wash and dry the person's genitals while sitting on the seat (Age UK, 2012c). Yet, automatic toilets may not be useful for people with dementia as they may be frightened of automatic flush and bidet-functions. Wherton and Monk (2008) described a prototype called the Friendly Rest Room with sensors to detect falls and adjustable toilet heights. This would eliminate the need for raised toilet seats, but the authors did not describe whether the seats were fully dementia-friendly; for example whether they featured bright, contrasting colours. Their prototype is not currently available to the public.

4.3.4: Feeding and eating ATs

Without assistance, some people with dementia may go hungry. For example, they may forget to eat (cognitive functional limitation), be unable to swallow (physical functional limitation), or their environment may restrict their ability to prepare food. Help with feeding and eating is commonly human: carers can either use verbal prompts or physically feed the care-recipient. The type of interaction between the carer and the person with dementia, for example the use of touch,

redirection, verbal prompts, and praise, can influence the amount of food consumed and ultimately weight maintenance, loss, or gain (Altus et al., 2002, Amella, 2002, Barratt, 2004, Chang and Roberts, 2008). Eating skills can be reacquired after a prompting intervention (Coyne and Hoskins, 1997). However, such help could require 35-40 minutes per person (Simmons and Schnelle, 2006); time that is not always available in care homes (Crogan et al., 2001). Furthermore, people with dementia may not understand that the carer is in fact assisting them, leading to challenging behaviours (Chang and Roberts, 2008). Research has also indicated that the social, cultural, religious, and ritual aspects of mealtimes should not be ignored (Amella et al., 2008, Barratt, 2004). Finally, it is important to recognise how inability to feed oneself could negatively affect the person's sense of dignity.

Assistive Technologies may be effective in managing poor eating behaviours (Kyle, 2011). For example, specialised cutlery may be: angled, have wrist-straps, have large or brightly-coloured handles, or be in the form of wide foam handle adaptations for typical cutlery. Rocker knives enable food to be cut with only one arm. Plates and bowls can have suction bottoms, tilted bases, or raised sides to enable the food to be pushed onto the fork or spoon more easily. Adapted mugs can have: insulation, multiple handles, angled bases or lips, sip-top caps, drinking spouts, or flexible straws. However, carers should be aware that straws could induce choking and fluid aspiration if it is brought to the back of the mouth too quickly, thus risking pneumonia (Crowe, 2003). All of these ATs may be trialled successfully with people with dementia (Connolly and Wilson, 1990). For instance, Griffin (1995) described a programme called 'Caring Hands' that provided eating interventions for people with dementia. The participants in their study experienced successful use of technologies such as plate guards and large-handled spoons, and one participant became able to initiate drinking on her own once liquid was presented to her in a transparent cup.

Appropriate caring and environmental modifications may also improve feeding and eating behaviour. Approximately half of eating-related disabilities among people with dementia are due to unsupportive environments (Slaughter et al., 2011). The surrounding environment is important for helping people with dementia to eat well and encourage them to maintain the skill of feeding themselves. Good lighting, contrasting colours, reducing distractions and clutter, and playing music can all be effective (Amella et al., 2008, Aselage et al., 2011, Aselage and Amella, 2010, Watson and Green, 2006). Recommendations by Cantley and Wilson (2002) for care home designers and managers include paying attention to the person's: nutrition (fluid and food intake), physicality (weight, oral health), and their social surroundings (flexible mealtimes, welcoming visitors). Finally, catering and care staff need to be aware of residents' likes and dislikes; this may include finger food

if a person prefers this to using cutlery. The environment should have minimum distractions, smell nice, and the table should be laid only immediately prior to meals. Care home residents, including those with dementia, may want to assist in laying the table, and should not be discouraged if they wish to do so. Dining 'family style' at small dining tables, instead of from armchair trays, can improve eating behaviour and reduce aggression among care home residents (Griffin, 1995, Melin and Götestam, 1981, Negley and Manley, 1990). It is possible that this may change for future generations of people with dementia, who may be more used to eating from their laps (Visser, 2015).

Hanson et al. (2011) systematically reviewed 25 studies to find out if the addition of high-calorie supplements, appetite stimulants, assisted feeding, modified diets, and other oral feeding options improved weight gain, mobility, and survival in people with dementia. Weight gain was the only successful outcome. As can be common in the literature on feeding and eating activities for people with dementia, the use of ATs was noticeably absent. A person with dementia may forget the skills for using dining cutlery and resort to using fingers to self-feed, although eventually even these movements can be lost (Griffin, 1995). Yet, ATs could help maintain the ability to use cutlery. Assistive Technologies may also aid the person with dementia to perceive that food is on a plate, before severe cognitive and visual impairments reduce the ability to sense its presence. As will be described in the discussion of design in section 4.8, bright (but not highly-patterned) colour contrasts ensure a person with dementia can distinguish between the plate, the food, and the table-setting. Barratt (2004) described an example of white fish in parsley sauce served on a white plate placed on a white tablecloth: if the person with dementia cannot perceive the food they cannot realise that they should eat it.

A last technological resort when a person cannot swallow is a feeding tube. Although it is an individual's human right to receive healthcare that can save or maintain their life (British Medical Association, 2001), such forced feeding, and the restraint that may accompany it, raises ethical issues (Norberg and Hirschfeld, 1987). Dennehy (2006) discussed the decisions regarding feeding tube insertion against the ethical principles of beneficence, non-maleficence, respect, autonomy, justice, and veracity. There are positive and negative reports of the effectiveness of feeding tubes (Dennehy, 2006), but it is generally found that using a feeding tube with people with dementia does not prolong life or increase nutritional health (Amella et al., 2008). A systematic review by Finucane et al. (1999) did not find conclusive evidence that tube feeding prevents aspiration pneumonia, malnutrition, pressure ulcers, reduces the risk of other infections (and in fact can cause infections), or improves survival, patient comfort, or functional status. Feeding tubes were perceived by

cognitively-intact patients who had experienced them as not equivalent to eating food and lacking the symbolic meaning given to the social event of eating a meal (Walker, 2005). Furthermore, forgoing the feeding tube has been associated with increased carer satisfaction with end-of-life care (Engel et al., 2006, Sanders et al., 2000). Therefore, for this thesis feeding tubes were not considered an *assistive* technology. Feeding tubes do not assist in eating behaviour or promote autonomy; rather they are a medical technology or coping strategy in response to a critical situation.

4.3.5: Benefits to people with dementia by using ATs for ADL performance

There are many ATs available to support the different difficulties people with dementia may have with performance of washing and bathing, grooming and dressing, toileting and continence, and feeding and eating ADLs. The promotion of AT use is already included in English social care policies and legislation for older people and people with dementia such as: the Mental Capacity Act (MCA) (UK Parliament, 2005), National Dementia Strategy (NDS) (Department of Health, 2009), Prime Minister's challenge on dementia 2020 (Department of Health, 2015), and National Service Framework for Older People (Department of Health, 2001). One reason is that receiving ADL assistance from human carers may further reduce the receiver's independence if they are required to fit in with others' schedules (French, 1998). For example, a person with dementia may receive formal carers in their home for washing and dressing every morning. This means that they cannot sleep until whenever they want, and that they have to go to bed whenever the evening carers dictate. Therefore, ATs may allow users to retain more autonomy than if they relied on human carers (Clarke et al., 2009, Gignac and Cott, 1998). Of course, the person with dementia must be enabled to make their own choices about the technologies they would like to trial and use for their ADL performance, to promote true independence (Tinker et al., 2013). Indeed, van Hoof et al. (2010) acknowledged that no single home modification will work for all people with dementia or their carers. Personalised care and appropriately tailored technology packages are therefore important. Unfortunately, to date there is little evidence of the effectiveness of ATs for dementia care (Fleming and Sum, 2014).

Appropriate and accepted use of ATs for ADLs and immobility, compared to receiving human care, have been shown to promote positive affect among physically-unhealthy but cognitively-healthy older adults (Lin and Wu, 2014). Use of ATs can also free informal carers' time usually dedicated to ADL assistance, to enable instead more social interaction with their relative (Garwood, 2010). This is because some ATs do not require the on-going co-operation or co-ordination of carers when used by a person with ADL needs (Agree, 1999). However, scholars have discussed whether ATs for ADLs

should be used as a substitute for human carers or as a supplement to their assistance, when the population under investigation consists of people with a clinical diagnosis of dementia. This discussion follows the presentation of reviewed literature for topic 3 below.

4.4: Presentation of reviewed literature for topic 3

Sections 4.5 to 4.8 of Chapter 4 cover the scoping review of literature for the third topic: carers' preferences, barriers, and facilitators with respect to the use of ATs by people with dementia in community settings. This begins in section 4.5 with a discussion on whether ATs used by people with dementia may supplement or substitute for human carers. Despite that much of this referenced work in particular was done in the USA on non-cognitively impaired populations and on mobility rather than ADL-related ATs, it was included for its importance due to its contribution to the debate on the role that ATs may have in dementia care. Some work was also presented which indicated that a population with poorer cognition may supplement, but not substitute, human care with ATs. Although this was not on dementia specifically, findings were useful when later designing interview questions for informal and formal carers' current and retrospective experiences.

In section 4.6, the key knowledge gaps resulting from the thematic analysis of reviewed literature are presented. These all concerned limited, or a complete lack of, evidence on a number of themes: how people with dementia begin to use ATs; where people obtained ATs; how use of ATs was maintained; and informal carers' perceptions of the role of ATs. For each of these themes, the most relevant articles were chosen in order to present some evidence. This meant that most referenced papers did not ascribe to the three core themes of being about dementia populations, ADL performance, or ATs for ADLs. Some were also conducted on non-English populations. That there were no or limited research findings for all themes further justified the need for this study, and clarified the final wording for research question 3. These gaps also aided the creation of interview questions for informal and formal carer-participants in this study.

Six ethical concerns are themed in section 4.7. Most papers referenced here were conceptual. Not all were dementia-specific but instead focused on ethics of technologies. Some empirical research was referenced to support a point, and this was dementia-specific when available. For example, the third ethical point made was that older adults may be resistant to ATs for appearance reasons. No literature applying this to people with dementia was identified in the scoping review, and this was indicated as a knowledge gap. Section 4.8 provides a short discussion on understanding dementia for

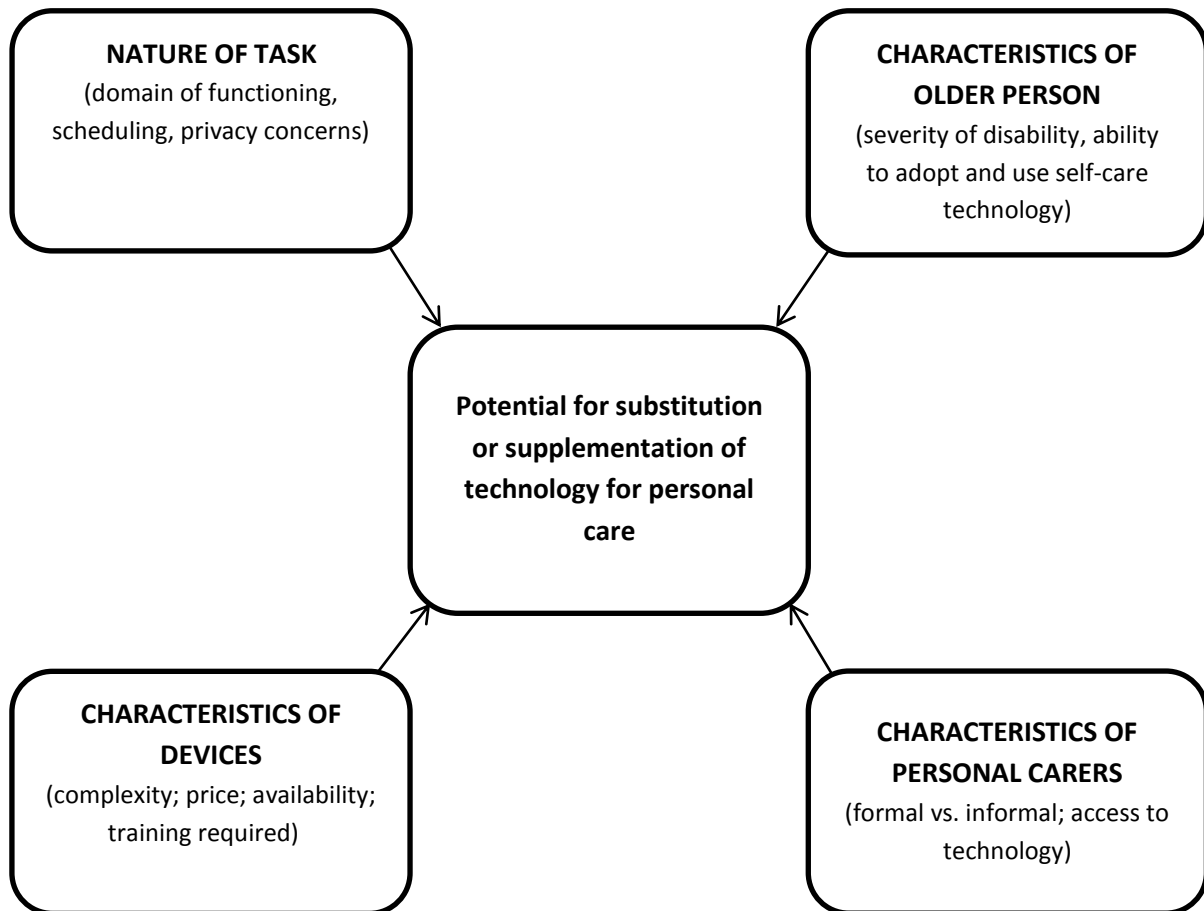
appropriate AT design. Rather than to present a knowledge gap, this section was included to advise the reader of some aspects of dementia not previously discussed such as visuo-perceptual difficulties, and to highlight characteristics of 'ideal' dementia-specific ATs. All literature was chosen for its focus on people with dementia. Both empirical and conceptual papers were referenced.

4.5: Assistive Technologies as a substitute for, or supplement to, human carers

The use of ATs in the life of a person with care needs is generally regarded as beneficial, and thus is included in the NDS (Department of Health, 2009). Yet, how they can best contribute to care, and the extent to which the technology should replace or assist a carer with ADL assistance, has been debated (Agree and Freedman, 2000). It has been demonstrated among a cognitively-healthy group that AT use is associated with fewer hours of human ADL care (Agree et al., 2005, Hoenig et al., 2003). This suggests that ATs may substitute for carers, thus reducing care costs and family stress (Agree et al., 2005). However, the issue remains as to whether ATs should substitute for human carers of people who have cognitive impairments in addition to physical difficulties. Ethical issues raised by AT use by people with dementia are discussed further in section 4.7.

Research findings suggest that there is no simple and generalisable 'yes' or 'no' answer to the question of whether ATs can substitute or supplement human carer assistance. The particular details of each individual's situation will be important to determine (Agree and Freedman, 2000). Not only will their specific cognitive and physical impairments and their environment need to be taken into account, but their attitude towards the particular device to be used will be important to determine whether it could be used alone. For example, Allen et al. (2001) investigated the use of mobility-related ATs as a substitution or supplementation for carers among a group of physically-frail older adults. The authors found that the use of simple ATs such as canes or crutches could substitute for human care, but that this was not possible in the use of more complex devices such as walking frames and wheelchairs. Therefore, whether ATs are able to act as a supplement to, or substitute for, human care depends on a number of factors. Agree and Freedman (2000) identified four categories of factors and created a model illustrating the capacity of ATs to substitute for, or supplement, human care. Their model is presented below in Figure 3.

Figure 3: Factors affecting the substitution or supplementation of carers for ATs



Source: Agree and Freedman (2000)

Figure 3 demonstrates the four contextual factors that may influence the potential of an AT to substitute or supplement carer assistance. The first, shown top left in the illustration, demonstrates that the nature of the ADL to be conducted, and the person's environment, are important considerations. For example, a person may prefer to trial a raised toilet seat when evacuating their bowels rather than having a carer help them to sit onto the toilet, but would prefer human assistance to comb their hair rather than trial a long-handled brush. A second contributing factor, shown top right on Figure 3, identifies that the characteristics of the person who needs assistance are important. This is especially so among people with dementia as they may be vulnerable to risk of injury during daily activities or neglect through poor ADL completion, and so may require human supervision. They may also be unable to learn how to use a new device, or be unconfident about using it alone. Continuing clockwise on Figure 3, a third potential contextual factor concerns the

characteristics of the carer and whether they would encourage its use; some may actively seek out ATs to trial whereas others may be resistant to their introduction. That is, although the MCA (2005) (UK Parliament, 2005) stipulates that decisions should be made in the person with dementia's best interests, and indeed use of ATs may be in their best interests, the carer may still restrict access to ATs. Finally, the fourth factor, bottom left in the illustration, acknowledges the device's characteristics. That is, the design of the AT, its ease of use, and other issues relating to each specific AT. All four of these factors were important to explore with informal and formal carer-participants in this thesis when discussing AT use for ADLS in community and care home locations.

However, Agree and Freedman's (2000) model was not based on data from people with dementia but cognitively-healthy, physically-frail older adults. Subsequent evidence has indicated that substitution is more likely for people without cognitive impairment (Agree et al., 2005). People with dementia may not be able to trade human assistance for technology. Agree et al. (2005) found that people with poorer cognition (not a diagnosis of dementia, however) were less likely to *substitute* care for AT use, but were more likely than cognitively-healthy participants to *supplement* human care with devices. Furthermore, they found that AT use by people with poor cognition was associated with both more informal and formal care hours. These results suggest that people with dementia may use ATs not to replace formal and informal carers but in conjunction with human assistance to achieve holistic, quality care.

Whether used to substitute or supplement carers, evidence suggests that the presence of ATs in a person with dementia's life can: improve the quality of care; minimise risk and enhance safety; delay further functional limitations; enable the maintenance of social participation; and finally reduce the likelihood of institutionalisation (Agree et al., 2005, Department of Health, 2009, Edlund and Björklund, 2011, Horgas and Abowd, 2004, Löfqvist et al., 2005, Mihailidis et al., 2004a). Yet, to date there is little knowledge about the ATs currently being used by people with dementia and their informal and formal carers in community settings; that is, in their homes. The following section presents key gaps in research that relate to actual AT use among people with dementia.

4.6: Lack of empirical evidence on ATs used by people with dementia living in the community

Although many ATs may be available, there has been a lack of research identifying the types of ADL-related ATs actually used by people with dementia and their carers when living at home (Gibson et

al., 2015). To date, most research instead investigates the design of the devices themselves (Abbott, 2007). It became apparent during the literature search and review for this thesis that published relevant research typically had one of two focuses: either it investigated ATs for ADL performance but excluded potential participants with dementia; or it examined the difficulties that people with dementia have when performing ADLs but excluded an acknowledgement of AT use. Yet, when studies were identified which did investigate the ATs used by people with dementia for ADL performance, the researchers usually only captured measures of 'use' or 'non-use' of the device. Such dichotomous outcomes do not enable an in-depth understanding of how ATs may contribute to daily life and dementia care. Summaries of these three areas of research are presented in turn below.

Much research that examined ATs and ADLs excluded potential participants with cognitive impairment (Agree et al., 2004). This is most likely due to the complex ethical considerations that investigators must take into account when conducting research with such a potentially vulnerable population. There is also concern among researchers about the reliability of data collected from people who may have poor recall or insight, yet research findings from physically-frail but cognitively-healthy older populations may not be applicable to people with dementia. For example, Mann et al. (1999) conducted a randomised controlled trial on 104 community-based, physically-frail older adults to investigate their use of ATs and environmental interventions over an 18-month period. These interventions included devices for ADLs, immobility, and sensory conditions. Results showed that participants who received intensive ATs and environmental interventions were less likely to have functional decline and pain, and reported lower healthcare costs than participants who received standard care. Therefore, AT use may promote independence and reduce morbidity. However, these results are not necessarily generalisable to people with dementia since they experience faster decline in ADL performance as a result of their additional cognitive impairment, compared to cognitively-healthy populations (Mihailidis and Fernie, 2002). Furthermore, the role that co-morbidities may play in influencing successful AT use within general and dementia populations requires investigation (Schäfer et al., 2012).

Another body of research observed from the scoping review investigated the functional status and ADLs performed by people with dementia. However, the researchers typically did not investigate the use of ATs. For example, Chang and Roberts (2008) conducted a systematic review of 71 articles with the aim of creating a detailed model of the determinants of feeding difficulty, in order to suggest potential interventions. The interventions included physical assistance, verbal cueing, and mirroring

actions. None of the 71 studies acknowledged the potential of appropriate ATs to support ADL performance. Excluding the use of ATs in research on dementia care may mean that the results are not a reliable and valid reflection of participants' lives, or miss a potentially useful intervention.

Of the studies which did include ATs used for ADLs by people with dementia, quantitative research strategies were the overarching method used to collect and analyse data. Use of ATs was often measured as 'use' or 'non-use', without more detailed or qualitative measurements of environment and context, frequency, and duration (Lenker and Paquet, 2003). Hawranik and Strain (2001) investigated the associations between cognition, disruptive behaviours, physical functionality, and formal service use in the community. Their measurement instrument required carers to comment on their relative's ability to conduct seven ADLs and 14 IADLs using a five-item scale: without help; some help from a device; some help from a person only; some help from a person and a device; unable to perform the task. The participants were not required to specify the device that they used. The results did not detail the cognitive and physical difficulties that people had when performing each ADL, nor separate between functional status and the human assistance or technologies used to help with these. Gaining an understanding of how ATs actually assisted ADL performance was not considered.

In conclusion, although there has been some research addressing ADLs, dementia, and ATs, and despite a range of appropriate ADL-related ATs, little empirical evidence exists on the use of such technologies among people with dementia living at home. Similarly, there is little knowledge about how people with dementia or their informal and formal carers assess their need for, and begin to use, relevant ATs, as the following sub-section demonstrates.

4.6.1: No knowledge concerning how people begin to use ATs

To date, there is no research investigating how people with dementia, or their informal carers, assess their need for ATs for ADLs. Focus groups with frail older adults without dementia showed that their confidence both in the expert who recommended the technology and in the information received were important influences on future AT use (Skymne et al., 2012). Getting used to the technology was important and determined by: the extent to which the physical and social environments facilitated its use; the feeling of safety the AT produced; and whether the user perceived their need for the AT as temporary or permanent (Skymne et al., 2012). The focus group participants in Skymne et al.'s (2012) study also discussed their negative perceptions of ATs; that their use can lead to a sense that they are unwell, and may limit their daily lives. The participants

also felt that the devices were physical obstacles, took up space, and caused tasks to take longer than they should (Skymne et al., 2012). Yet, they also perceived ATs as necessary to get through daily activities, felt that they saved energy, and provided a sense of relief because they could perform ADLs alone (Skymne et al., 2012). However, the study was conducted on a Swedish population of physically impaired, but cognitively-intact older adults. Thus, we continue to know little about how people with dementia and their informal carers assess their need for, or feel motivated to start using, ADL-related ATs. The uptake of ATs among people with dementia may occur for different reasons: it may be more reliant on the carer's own perceptions of confidence and worth than those of the person with dementia; if they lack insight into their difficulties they may be unable to identify their need for ATs.

In addition to a lack of research on perceptions of need for ADL-related ATs, there is also little work investigating how people with dementia become technology users. Swedish case study research, based on three people with dementia, showed that to be most beneficial to their lives ATs were frequently adapted or combined with other devices (Rosenberg and Nygård, 2012). Participants' use of ATs was determined by the meaning they applied to the technology and what was communicated back to them, even if they had received instruction and training in the correct usage (Rosenberg and Nygård, 2012). To illustrate, one of the participants was provided with a vividly coloured magnetic memo-board to plan her weekly schedule. Instead she used it to display important papers. As this was not its intended purpose, the OT subsequently removed it. This finding shows that it is difficult to anticipate outcomes without acknowledging the context and interaction between people and the environment. The findings also demonstrated that people with dementia presumed that the professionals who prescribed the ATs knew their needs best, even though they did not always think the ATs were a match to their perceived needs. Thus, it is important to know who has decision-making power for AT use in dementia care. Rosenberg and Nygård's (2012) study elicited rich data that took into account the context surrounding the use of ATs, and in particular the use of ATs for community-based people with dementia. However, research also needs to focus on ATs for ADLs, as the devices investigated in Rosenberg and Nygård's (2012) study were time and memory-related such as calendars, speaking clocks, and memo-boards. A full understanding of how and why people with dementia came to use ATs for ADLs cannot be made without also exploring how they or their carers obtained the devices.

4.6.2: Lack of evidence outlining where ATs are obtained and the role of formal services

There has been little research on where people with dementia and their family members sourced the technologies they used, and how they became aware of these ATs (Gibson et al., 2015).

McCreadie et al. (2006) conducted focus groups with 28 cognitively-healthy AT users aged 75 years and older to examine the various ways that information can reach community-dwelling older adults. For example, materials can be obtained from medical surgeries, neighbourhood chemists, and local libraries (McCreadie et al., 2006). In another study, Jensen et al. (2009) demonstrated that people with dementia sometimes acquired their technologies accidentally, typically they had to educate themselves about what was available, and pay for it privately. However, the technologies investigated in Jensen et al.'s (2009) study were not specific to ADLs. Other research has highlighted the importance of the location within which the person resides, as the availability of services varies between LAs (Agree, 1999). In more recent work by Gibson et al. (2015), informal carers indicated that ATs provided by formal services were usually the result of an acute event, such as a fall, or due to luck such as chance meetings with health and social care professionals. Even then, families were unhappy about ATs provided by formal care services, as they had little training on the devices or follow-up to ensure use was maintained (Gibson et al., 2015).

Yet, research and policies have highlighted the crucial role of health and social services and other responsible bodies in providing ATs to those who needed them (Cahill et al., 2007, Molin et al., 2007). Anyone who may benefit from ATs has the right to access them, but social services or health professionals may deny this right if they deem the use of the device unnecessary (Bjørneby et al., 2004, Rosenberg and Nygård, 2012). Such negative attitudes towards AT use may lead to discrimination and restrict its availability. For example, Bjørneby et al. (2004) discussed a day care centre whereby staff and potential users were interested in a new entertainment technology but managers felt it was not in the users' best interests. Alternatively, some professionals may feel restricted by their organisation's procedures when trying to provide information on ATs (McCreadie et al., 2006). Finally, both professionals and informal carers may be resistant to ATs if they have concerns about device misuse and other ethical considerations. These potential issues are described later in section 4.7.

Much research has demonstrated that participants sometimes acquired their technologies privately (Wright et al., 2005). Clough et al. (2007) found that many individuals in communities had to do without the expertise of an OT when they needed it, so they often sourced and fitted ATs they perceived they needed themselves. Cost was also an issue for prescribers of funded ATs, so

distribution was often restricted (Bjørneby et al., 2004). Yet, Mihailidis et al. (2000) showed that ATs were relatively inexpensive compared to the cost of funding formal care services. Cost-efficiency is essential in order for formal services to justify provision (Molin et al., 2007). However, Mihailidis et al. (2000) also stated that public services should not be the only providers of ATs. If people bought their own equipment, ATs may become more prevalent in shops and costs could fall. It is hoped that the market will widen as younger generations, who may be less resistant to technologies, age (Fleming and Sum, 2014). There is a need for educating the general public on the benefits of appropriate ATs. However, little health promotion work has been done to demonstrate the benefits of ATs and where they can be obtained (Cash, 2003). Therefore, in this research how and where people with dementia and informal carers obtained ATs for ADLs, and their perceived barriers to this, were explored.

Finally, no articles were found in the scoping review on the perceptions of informal carers with regards to their, and the care-recipients', relationships with formal services when accessing or using ATs. For example, there was no evidence about how people with dementia or informal carers felt about formal carers entering their home, changing continence pads, assisting with stand-aid hoists, or using eating technologies with them. Another knowledge gap concerned a lack of research investigating how use of ATs for ADLs was maintained over time, and whether maintained use was related to the presence of human carers. This issue is discussed below.

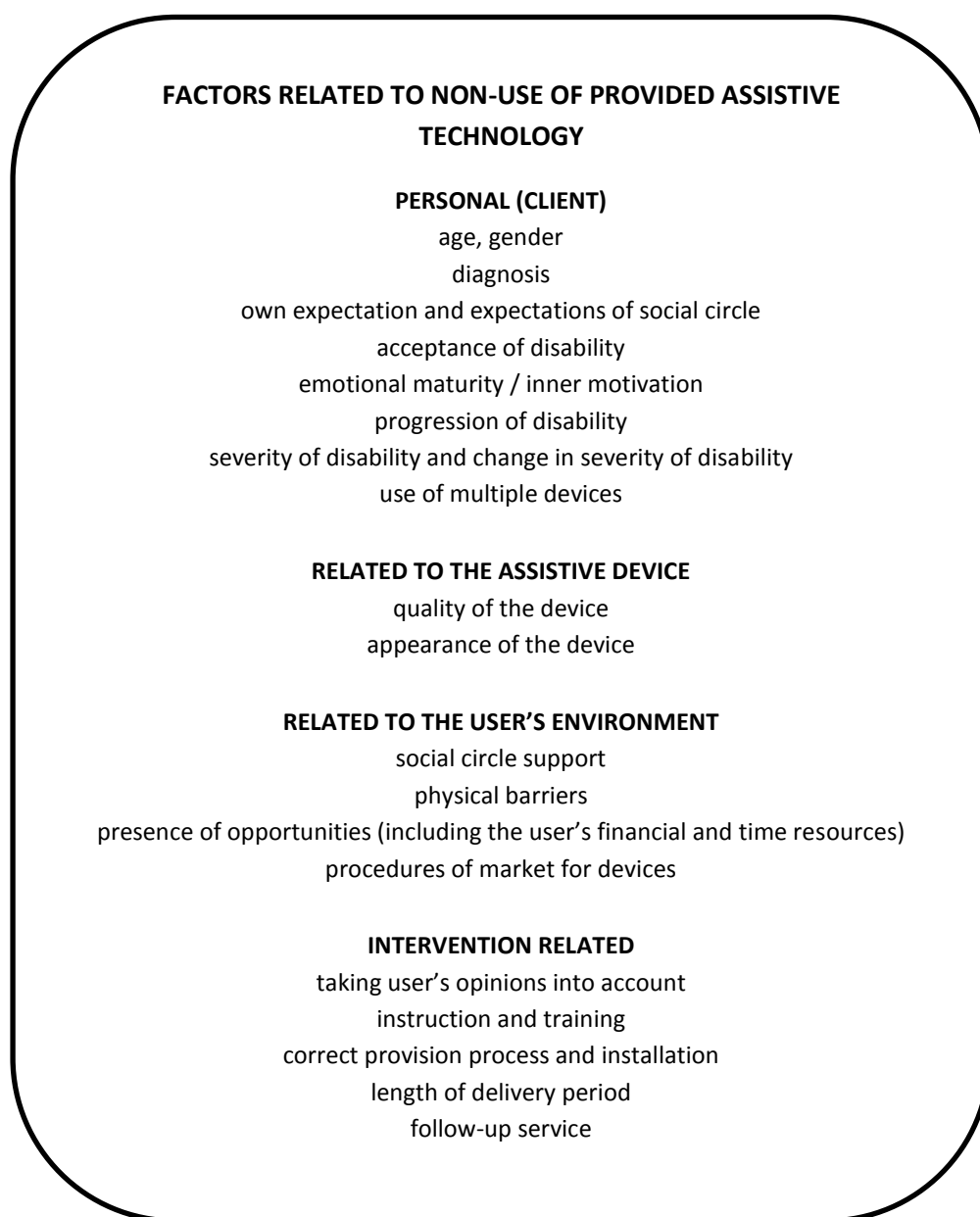
4.6.3: Gap in knowledge of how use of ATs is maintained

The scoping review produced little understanding on how use of ATs is maintained in the community or in care homes, although researchers acknowledge that user acceptance is important for maintaining technology use (Carswell et al., 2009, Rosenberg et al., 2012). It is therefore important that research is conducted to assess the acceptability of AT use both at home and in other locations such as a care home, and how that use is maintained over time. Some studies have shown that introducing a device in the early stages of dementia can ensure that the person becomes more used to it (Cahill et al., 2007), but changes in the person's needs and abilities over time should be monitored (Pew and Van Hemel, 2004). Mann et al. (1996) followed 19 people with dementia for one year and demonstrated that as their cognition worsened, participants stopped using devices that assisted their cognitive impairment and only maintained use of ATs for physical functioning. In this study, how people with dementia changed their use of ATs over time and between care locations was explored.

Abandonment of an AT is also an issue for people with dementia, although research has shown that aids for daily living may be less likely to be abandoned compared to other technologies such as those for respiration, hearing, screen readers, or communication (Martin et al., 2011). Understanding the use and non-use of devices is important for both commissioners of research into technologies for dementia care, and commissioners of dementia care services when deciding which ATs to provide. Wessels et al. (2003) conducted a comprehensive review of literature investigating non-use of ATs. They produced a list of resulting factors, illustrated below in Figure 4. The literature they reviewed was not specific to people with dementia or ADL-related ATs, but may be relevant for such a group. Four categories emerged: personal factors, factors related to the device, factors related to the environment, and intervention related factors (Wessels et al., 2003).

Figure 4 demonstrates that person-centred factors such as a diagnosis of dementia, acceptance of the ADL disability, and insight into the condition, may lead to the non-use of ATs for ADLs. Wessels et al. (2003) also identified the importance of the environment for AT use and non-use. The extent to which the home environment suits the new AT needs to be considered during OT assessments (Molin et al., 2007, van Hoof et al., 2010). Home characteristics are sometimes ignored when social services provide ATs but these could severely impact their effectiveness (Agree, 1999). Finally, Figure 4 demonstrates that the design of the device must be appropriate for people with dementia; design is discussed further in section 4.8. A final gap in empirical evidence, and one that was only briefly acknowledged in Wessels et al.'s (2003) model in Figure 4, is the perceptions of ATs in the person's social circle. There is a lack of knowledge about the perceptions that informal and formal carers have regarding the contribution that ATs can make to dementia care; this is discussed below.

Figure 4: Potential reasons for non-use of ATs



Source: Wessels et al. (2003)

4.6.4: Lack of research capturing carers' perceptions of ATs

A key gap in research concerns informal and formal carer perceptions of ATs, including their preferences for devices and their perceived barriers to technology use. Most of the research reviewed measured the 'success' of an AT as its ability to be operated by an older adult or person with dementia, rather than whether potential users or carers perceived it would fit into daily life. Yet, as dementia affects people in different ways, collecting qualitative accounts of how ATs contributed to their particular experiences may be useful.

The main criticism of the reviewed AT research was that few studies investigated the perceptions of potential users on the success of the device in context. That is, typically research to test an AT used measures of 'success' only within laboratory settings, and again on 'use' or 'non-use'. Studies did not collect users' perceptions of the role of the AT in contributing to their daily lives; whether people with dementia and their carers felt the product was useful and worth the money, time, and effort to obtain, learn, and use it was not captured. For example, Zingmark and Bernspång (2011) compared use of bathroom ATs to usual formal care services among cognitively-healthy older adults. The outcome was that the control group continued to have poor ADL performance. However, the authors did not capture participants' satisfaction with the device, and therefore could not determine whether the bathroom ATs made a meaningful contribution to the users' sense of well-being, or even whether they intended to continue to use the technologies. Although some research conducted on cognitively-healthy older adults found that AT use was related to feelings of safety and to the lack of effort required, participants provided their reasons using pre-designed tick-box responses (Hägglom-Kronlöf and Sonn, 2007). By ignoring or pre-empting users' perceptions on ease of use and satisfaction, the success of a new device in real life may be hindered (Hagen et al., 2004).

People with dementia have differing needs, experiences, and expectations. As such, qualitative data are needed on the preferences that people with dementia and carers have with regards to technology use in the community and in care homes. These data could then take into account other factors that may influence AT use, for example, the severity of cognitive symptoms and their current formal and informal care networks (Sixsmith, 2006). Meaningful impact on quality of life, such as a reduction in stress, is also an important measure of success beyond whether a device was used or not (Bharucha et al., 2009). To illustrate, Nochajski et al. (1996) qualitatively explored users' preferences for AT and demonstrated the validity of this method for eliciting meaningful and useful data. The authors found that although people with cognitive impairment accepted and used devices mostly for physical impairments (such as grab-bars and cutlery with easy-grip handles), they reported greater user-satisfaction with cognitive devices that aided memory and simplified tasks. Thus, the study found that feelings of dissatisfaction with a device were often due to the cognitive capabilities of the user rather than to the device's design or any perceived stigma. Ensuring that individual needs are taken into account via in-depth discussion with potential users is therefore important (Cahill et al., 2007).

'To me instead of researching how many people are in an age group . . . you need to talk to people and get a real feeling for what it is they need. You see everybody who is 90 doesn't need the same thing!'

The above quote, from an 84 year-old (cognitively-healthy) woman (Krothe , 1997, p.223), highlights the need for a thorough personal understanding of the potential recipients of ATs (Sixsmith, 2006). Such results can then be used to design and promote targeted ATs and services.

The perceptions of informal carers on the value of equipment to help their relative with dementia are salient and related to successful use in the community. This is particularly important for people with severe dementia who may be unable to participate in focus groups or interviews. Yet, while carer perceptions have been used to assess perspectives on home modifications for people with dementia (Calkins and Namazi, 1991), they have rarely been used to investigate ATs used by people with dementia for ADLs. A particularly informative study by Edlund and Björklund (2011) conducted interviews with 10 family carers of older adults, cognitive health undisclosed, on products and technology use. Results demonstrated that participants considered ATs essential for daily activities, for example, because they alleviated the effort needed to assist with physically strenuous activities. Their results showed that the family carers' motivation was a leading determinant of the technologies used by their relative. The interviews also highlighted carers' perceived barriers to technology use; for many accessing information on products was difficult, and they did not want to search the World Wide Web for information. However, those family carers with professional experience of healthcare felt empowered to assess their relative's need for ATs and request this type of assistance. Resistance from both the carer and the care-recipient to trialling new products was also reported. Other barriers included: feeling that an AT was forced on them; wanting to manage on their own even when an AT would make caring easier; and lack of willingness to learn about new devices, even if others were already used. Communication difficulties with Occupational Therapists (OTs) who had prescribed the technology also hindered AT use, and follow-up appointments were often necessary to ensure correct usage. In conclusion, these detailed results demonstrate that it is important for family members to perceive the need for ATs to maximise their use by a relative.

In a second relevant study, interviews and focus groups were conducted with 16 informal carers to investigate perceptions of technologies used with their relatives with dementia (Rosenberg et al., 2012). However, the authors focused on technologies for memory, planning, safety, and for IADLs such as shopping. Results demonstrated that carers felt that safety was so prime a concern that this

overshadowed ethical concerns about privacy. However, the two studies were conducted in Sweden concerning older adults with an unknown cognitive status (Edlund and Björklund, 2011), and on a dementia population but without a focus on ADLs (Rosenberg et al., 2012). More recent work on family members' perceptions also indicated they had positive and negative views on ATs for dementia care (Gibson et al., 2015), but again did not focus specifically on devices for ADL performance. In summary, the perceptions of people with dementia and their family carers toward ATs in England are needed, given that services in England can vary from those of the other UK countries as discussed in Chapter 2. Moreover, data on formal carers' perceptions of the use of ATs for ADL performance in dementia care are scarce (Innes, 2009). Carers' perceptions are important as their real-world experiences may enable them to identify ethical considerations not previously considered in academic literature. Some potential ethical issues are described below.

4.7: Ethical considerations for ATs used by people with dementia

The potential adverse aspects of ATs used to assist people with dementia to perform ADLs need to be acknowledged and debated (Cash, 2003, Mahoney et al., 2007). Technology use is not neutral, and in fact may have a negative transformative effect on the person's behaviour (Sharon, 2014) and well-being. These transformations may be a result of: the misuse of the technology; an over-estimation of its ability to eliminate risk; the person with dementia's perception that the use of an AT would change the way others view him or her; or the person's view that they have not been able to choose their own AT. A further concern may be that the use of an AT removes the need for the presence of humans completely, which could contribute to isolation. It is also debated as to who AT use truly benefits and whether the person with dementia or their carer is truly the 'user'. These six ethical issues are discussed below. The debate around the infringement of civil liberties surrounding tracking technology will not be discussed (Cahill et al., 2007, Mihailidis et al., 2004a), as this thesis focused on the performance of ADLs and not getting lost while walking outside (previously termed 'wandering') (Marshall and Kate, 2006).

The first ethical consideration for ATs for ADLs is the potential misuse of a device through its overuse (Bentley et al., 2014, Cheek et al., 2005, Rialle et al., 2008). Too much technological support could act to remove the capacity of the person to adapt and compensate to challenges (Pew and Van Hemel, 2004). For example, a person with dementia may use a walking frame at all times to assist with their gait. By using it every time they walk they are reducing their risk of falling; yet there is also a risk that they are affecting their chance to improve or maintain some physical function such as

balance, muscle strength, and flexibility. If they trip, their body may be less able to react quickly and potentially prevent a fall. Therefore, a safety-enhancing and labour-saving walking frame could ultimately lead to a poorer state of physical health and sedentariness, as the person moves less and does less for themselves (Barzel, 1991).

The second issue concerns if potential and actual users wrongly-perceive that the AT reduces the risk of danger: fall, injury, or death. There is a concern that some ATs may provide a false sense of security. Yet ATs can only manage risk, not remove it completely. Some degree of risk is inevitable if people with dementia are to be encouraged to perform ADLs for themselves for as long as possible. Therefore, the person with dementia and their carers should discuss what level of risk is acceptable in order to maintain the person's well-being and dignity, and what the perceived and actual risks are. A balance should be made between allowing people with dementia to take risks and attending to the carer's own needs by helping them to keep the person with dementia safe. However, some technologies may 'reduce risk' to the extent that they enable too much control over the person; for example, Ben Mortenson et al. (2012) observed wheelchair lap belts worn by care home residents, in place to reduce falls, to over-restrict them and impinge upon their liberty.

A third issue with AT use is that it may contribute to damaged psychological health if the person with dementia feels it means they are viewed negatively by others (Demiris and Hensel, 2009, Nygård, 2008). Pendant and other telecare alarms have been cited by some older adults as attracting negative attention as it presents them to others as having high care needs (Courtney et al., 2007). Damaged psychological health or altered behaviour could also be extended to informal and formal carers, for example, if surveillance-type technologies are introduced in care homes (Social Care Institute for Excellence, 2014). Potential users could ultimately reject the device, even though they may have benefitted from it. Indeed, research has demonstrated that older adults are often resistant to the use of ATs for appearance reasons (Bentley et al., 2014, Häggblom-Kronlöf and Sonn, 2007, Hoenig et al., 2003). This therefore presents a barrier to device use (Bossen et al., 2015). However, this has not been explored with people with dementia, who may be as concerned about their appearance as any person. Alternatively, ATs could positively contribute to maintaining appearance. For example, Lawton (1998) discussed continence technologies such as continence pads or catheters as 're-bounding' a person and informal carer back into a socially acceptable state.

Fourth, the person with dementia's thoughts and wishes should at all times be the focus of informal and formal carers when designing appropriate care plans. If a person with dementia does not want

to use a technology they should not be obliged to obtain and trial it. Although the presence of ATs could make a positive contribution to someone's life, for example, by increasing safety (Garwood, 2010), decision-makers should stay mindful of the person with dementia's wishes. Technologies may not be appropriate for all; if an AT does not meet their individual needs and preferences it may be ineffective or even cause confusion or distress. Technologies have the potential to disable a person with dementia as well as to enable them (Shinohara and Wobbrock, 2011).

A fifth ethical concern may be if the use of an AT removes the need for carers and thus human contact (Bentley et al., 2014, French, 1998, Sixsmith, 2000). Indeed, Skymne et al. (2012) demonstrated that frail older adults agreed in principle to the benefits of ATs but were easily able to perceive the risk of isolation:

"Sometimes when you get an assistive device that you like and is very useful, the help you get from friends and relatives is not as natural any more. They then think one can manage alone" (Skymne et al., 2012, p. 199).

Human contact is crucial for people with dementia and contributes to their sense of well-being (Branfield and Beresford, 2010). Human contact is also important for promoting AT use among people with dementia (Mahmood et al., 2008). It is always necessary to consider whether the new AT could potentially increase the user's isolation or alternatively enhance their social contact, for example by helping them to go out more often (Demiris and Hensel, 2009). However, Agree (1999) emphasised that ATs can have advantages over human care as they do not require on-going co-operation with another person, something that itself can impact on well-being.

The sixth ethical issue considers which person is the true beneficiary of AT use in dementia care (Bonner and Idris, 2012, Gibson et al., 2015, Godwin, 2012). To illustrate, a person with dementia received a DFG to install a wet-room complete with shower and sink seats, hand-rails, raised toilet seat, and more. It is unclear whether the advantage of the new environmental modifications and ATs was really: for the person with dementia to use the wet-room to perform tasks alone and safely; for the family member, as it reduced the time spent on caring tasks and stress; for the formal carer who used it to save time during their visit; or for the Government which provided the DFG with the overall aim of reducing care home admissions and therefore expenditure. Nevertheless, if the introduction of the wet-room enabled the carer to have a more meaningful time with the person with dementia, the advantages are perceived to be numerous (Garwood, 2010).

In summary, the ethical issues presented here are salient for people with dementia, informal carers, and health or social care professionals. These issues may even become barriers for the uptake of ATs for ADL performance (Godwin, 2012). Technologies should only be used in conjunction with an appropriate living environment, appropriately trained carers, and for an appropriate activity. The literature suggests that they should not be used to replace direct human contact. Furthermore, their design should be suitable to the needs of people with dementia.

4.8: Understanding dementia for appropriate AT design

Good design is key to enabling a person to have the best experience of care (Forlizzi et al., 2004). If a technology is to support people with dementia, it needs to be attuned to their capabilities (Boger and Mihailidis, 2011, Bossen et al., 2015). Technology designers should co-produce with people with dementia to ensure appropriateness (Boger et al., 2006, Mountain, 2013, Span et al., 2013, Wherton and Monk, 2008). For example, use of ATs may be rare not only because learning to use them is challenging for people with dementia, but because of additional cognitive symptoms such as apraxia (difficulties with motor co-ordination) (Orpwood et al., 2004, van Hoof and Kort, 2009).

Designers, engineers and those considering home or environmental modifications need to be aware that dementia also impairs the senses such as smell (Duff et al., 2002) and vision (Jones and van der Eerden, 2008). For example, people with AD may experience visuo-perceptual mistakes called hallucinations (Jones and van der Eerden, 2008). Hallucinations can occur because of impairments in texture discrimination; patterned and reflective surfaces may be viewed as wet patches, holes, or shadows (Jones and van der Eerden, 2008). Colour perception also becomes impaired as dementia progresses; in particular blue, purple, and green aspects of the colour spectrum may be perceived as grey (Jones and van der Eerden, 2008). Visuo-perceptual difficulties were manipulated in the past to control the behaviour of care home residents with dementia; for example, the placement of mirrors or patterned carpets at exits to prevent people with dementia from using them. Now, after considering the frightening effects these methods could have, other interventions are used to prevent people with dementia entering forbidden areas. For example, doors are painted the same colour as surrounding walls so that they blend in, or memorabilia displays distract attention (Jones and van der Eerden, 2008). Visuo-perceptual aspects that need to be taken into account when designing ATs include ensuring that strong colour contrasts are presented; for example, the use of a dark placemat to make a white plate stand out (Beck et al., 1993). Manufacturers of ATs have a

responsibility to understand issues such as these in order to produce appropriate, effective technology. For example, when designing room signs for way-finding it is necessary to: keep the sign a bright colour, a matt texture, uncomplicated, and not highly patterned.

The most useful types of ATs for people with dementia may be those which are 'passive' and do not require activation to operate, such as fall and water-level sensors (Bonner and Idris, 2012, Riikonen et al., 2010). Indeed, recommendations on effective ATs for people with dementia include that they should not require any learning and require minimum user interaction (Orpwood et al., 2004).

Devices that meet these criteria may also be those which are low-cost, such as elasticated shoelaces or Velcro fastenings; these may be used more often in the community than smart technologies that also meet the criteria but are expensive. Indeed, financial constraints may be an important barrier to AT use, especially as people living in the community may be required to fund their own technologies if they exceed the threshold set by the means test, as discussed previously in Chapter 2.

4.9: Chapter 4 summary

In this chapter, ATs were introduced as a type of external support to assist with the ADL performance of people with dementia. Technologies can either expand the bodily capacities of the individual, modify their environment to alleviate some task disability, or reduce some task complexity. There is some concern whether people with dementia can, or should, use ATs without human supervision or assistance owing to complications resulting from cognitive impairment. There are also multiple key gaps in knowledge concerning: current and actual use of ATs for ADLs in community settings; how people with dementia and their carers find out about relevant services and available ATs; and how use of ATs is maintained by this population. An understanding of these issues will be important for designing appropriate technology policies, marketing strategies, and for providing dementia care services.

Furthermore, people with dementia and their carers may have particular barriers to AT use that differ from those of cognitively-healthy but physically-frail older adults. Yet, even if barriers are overcome, a time may come when a person with dementia may need to relocate to a 24-hour care facility. As such, in the following chapter the discussion continues with an investigation of the crucial 'tipping point' triggers for institutionalisation among people with dementia; how relocation decisions are made; and whether the presence or non-use of ATs contributes to these decisions.

Chapter 5: The transition from community to care home

The previous two chapters showed how, according to the disablement process model, people with dementia may present with ADL disability (Nagi, 1991, Nagi, 1965), and the ways in which human and technological support may assist with the performance of ADL-related tasks (Verbrugge and Jette, 1994). In this chapter, the relocation of people with dementia into a care home as their cognitive and physical functional limitations progress is discussed. For this study, relocation to an institution refers to placement in a residential care home (where social care for ADLs is provided) or in a residential care with nursing home (where health and social care is given) (Alzheimer's Society, 2014c). The two are referred to under the umbrella term 'care home' throughout this thesis. The phrase 'at risk' for care home placement was not used in this thesis as this phrase may lead the reader to automatically consider institutionalisation as negative, whereas there can be positive aspects to care home life.

The first section of Chapter 5 discusses the presentation of literature exploring institutionalisation. Then, the concept of residual disability is introduced as a hypothesis to explain why institutionalisation may be inevitable, even with carers and ATs to support ADLs. This is followed by a brief discussion of reasons why people with dementia may prefer to remain living at home and receive ADL assistance there. Then, research evidence identifying the triggers of institutionalisation pertinent for people with dementia is presented. This is followed by discussion of research which investigated decision-making around institutionalisation of people with dementia: who is involved in the decision, and a theoretical model of how such decisions may be made. The scoping review highlighted that both the triggers and decision-making fields of research typically ignored the contributory role of AT use in community settings.

The presentation of literature exploring the lives of people with dementia who reside in care homes is then discussed. The benefits of living in a care home to people with dementia are presented. Once again, exploration of the use of ATs in institutions, and resulting contribution to dementia care there, was notably absent in the literature. Research exploring relationships that informal and formal carers have with care home residents with dementia, and the contribution families may make to ADL assistance there, is then discussed. The final chapter section highlights the dearth of knowledge concerning the extent to which ATs are used in care homes, by whom, and when.

5.1: Presentation of reviewed literature for topic 4

Sections 5.2 to 5.5 of Chapter 5 cover the scoping review of literature for the fourth topic: the tipping point for the person with dementia to relocate to a care home, and how institutionalisation decisions are made. In Chapter 3, a conceptual introduction to disablement was presented prior to the discussion on ADLs and social care (human and technological assistance). Here again it was felt that discussion for topic four should be preceded by theoretical work on understanding why disability may lead to a relocation of care. Thus, in section 5.2 the discussion focused on the role of underlying and residual disability on institutionalisation. These terms had first been identified when reviewing the literature for previous topics, and were introduced by authors frequently cited in this scoping review: Agree and Freedman (2003), and Verbrugge and Jette (1994). Whilst American and slightly older, the concepts and model used in this section felt relevant to the topic at hand. The Agree and Freedman (2003) model was used because it was the only identified paper on concepts of ADL difficulties and institutionalisation that acknowledged that ATs may contribute to reducing underlying disability. Although some empirical research findings exploring these concepts were referenced, this work was done by the same authors and thus may have been subject to some bias. Nevertheless, it was perceived as a framework that may usefully aid data analysis later in this exploratory study.

Section 5.3 continues with the first of two debate sections on institutionalisation which arose from the thematic analysis of literature for the scoping review. This section highlights the reasons that people with dementia would prefer to remain at home. Papers were perceived to fall into three sub-themes, and those referenced within were chosen for their relevance to the argument presented. Here, some older papers were used when defining some concepts such as 'environmental-press' or the 'sick role', as it was preferred to reference original authors. Not all data in this section were dementia-specific, reflecting a need for more work in this area. The counter-claim to the institutionalisation debate explores the benefits of relocation to a care home, and is presented later in section 5.7.

Two other themes which were identified when appraising data for this topic explored the experience of institutionalisation further. They were twofold because they could be divided into research which used quantitative data to identify triggers for institutionalisation and that which qualitatively explored decision-making around relocation of care. These are presented in sections 5.4 and 5.5 respectively. Only papers using populations with dementia were referenced for section 5.4 on

statistical triggers. Some grey papers were used to refer to the UK context, such as the number of care home beds filled by people with dementia. Only those papers of most relevance and with strength of design were preferred for this section. Empirical research identified multiple factors that could influence institutionalisation; those related to the three themes of dementia (or at least indicated cognition), ADL performance, and AT use were of most interest. However, the other variables, such as socio-demographic circumstances and informal carer characteristics, were presented due to their significance. Crucially, it was observed that no relevant research included the use, or non-use, of ATs in their study designs.

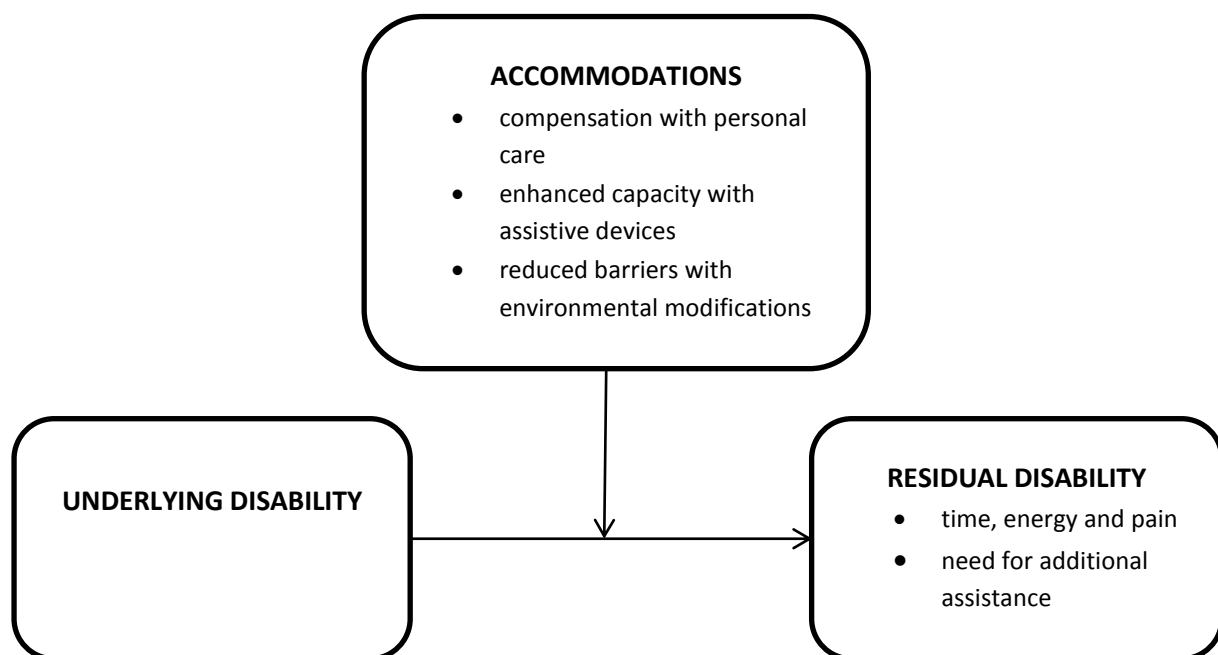
In addition to the identification of predictors for institutionalisation, other research focused on the experiences of making relocation decisions for older adults. This is presented in section 5.5. First, a discussion on the legal framework was made, which necessitated the reference of grey literature. Then, peer-reviewed academic papers were used to explore decision-making. It was of interest to identify any models that may conceptualise relocation decisions for care-recipients and informal carers. The Caron et al. (2006) decision-making model was deemed the most relevant for this exploratory study given its inclusion of multiple factors and focus on a dementia population. As with the underlying and residual disability model present earlier, it was perceived as potentially relevant to later study findings. The model was, however, criticised within the section for its lack of country context, lack of subsequent application in research, and no explicit references to the role of ATs. Indeed, like the section preceding it, it was identified that a key knowledge gap for this topic concerned little evidence on the role of ATs for ADLs towards relocation triggers and decisions concerning people with dementia. This contributed to the finalisation of research question 4, and the desire to explore the role of ATs in institutionalisation.

5.2: Residual disability may explain the need for care relocation

As discussed in Chapters 3 and 4, human assistance and ATs for ADLs may slow the disablement process either by reducing the impact of cognitive and physical functional limitations or by modifying the environment (McCreadie and Tinker, 2005). Yet, although carers and technologies may buffer the difficulties the person would have experienced (Allen et al., 2001), they are not always able to eradicate the person's disability completely. Verbrugge and Jette (1994) used the terms 'underlying disability' and 'residual disability' to distinguish between the person's (dis)abilities prior to and after receiving help. Underlying disability is the person's disability, as a result of their functional limitations and environmental demand, when performing ADLs alone (Verbrugge and Jette, 1994).

Residual disability is the remaining difficulties that the person experiences when performing an ADL, even with: human help, technological assistance, or environmental modifications (Verbrugge and Jette, 1994). Figure 5 below illustrates Agree and Freedman's (2003) model of the link between underlying and residual disability, and the accommodations which may act to reduce underlying disability: personal care (human carers), ATs, and environmental modifications. For example, a person with dementia has difficulty eating food from a plate: he or she stares at the food for a long time, is unable to hold a fork firmly in their hand, and drops food frequently. This demonstrates the person's underlying disability (Agree and Freedman, 2003). Yet, with the introduction of a brightly-coloured tablecloth to enable the person to perceive the plate, a large-handled and angled 'spork' (fork-spoon hybrid) to enable food to be scooped and held on the utensil more easily, and a carer to verbally prompt the person to perform actions, they may be able to feed themselves. However, some difficulties with eating may still remain; this is the person's residual disability (Agree and Freedman, 2003).

Figure 5: Accommodations to reduce underlying disability



Source: Agree and Freedman (2003)

Research has shown variations in residual disability according to the accommodations used by or with the person. For instance, Agree (1999) showed that people with physical functional limitations aged 70 years and older who used ATs-only for ADLs reported less residual disability than people who used carers-only or had both carers and ATs. Similarly, Verbrugge et al. (1997) found that people using ATs-only had a better chance of improving their residual disability than people who relied on carers-only or both types of assistance. Three patterns of preference were also observed among Verbrugge et al.'s (1997) participants, who were aged 35-90 years old and had physical functional limitations: they all preferred ATs prior to receiving assistance from human carers; males were more likely to use ATs-only compared to females who were more likely to use carers-only; and adults aged 75 years and older were more likely to use any type of assistance compared with younger participants (Verbrugge et al., 1997). However, Agree and Freedman (2003) found that people who used ATs-only had less initial underlying disability with ADLs than people who used part or complete human care. That is, people who preferred to only use ATs experienced less difficulties at baseline compared to others. Nevertheless, these studies provide insights into: the benefits of ATs for ADL performance; the potential of devices to reduce the impact of disability; and that people are willing to use technology when the alternative is assistance from formal carers. However, most of these studies were conducted on physically-unhealthy but cognitively-healthy populations. Therefore, the participants would have been able to reason and weigh up decisions regarding the type of assistance they chose. As dementia affects cognitive functioning including: insight, reasoning, planning, and understanding consequences (Cahill et al., 2007, Sarafino, 2006), additional difficulties in the adoption of ATs may be present for those with dementia. Thus, in this study, the reasons for use and non-use of ATs for ADL disability by people with dementia were captured.

Exploring remaining difficulties post-AT use are important as it has been hypothesised that the continued presence of residual disability is likely to lead to a decision to institutionalise (Verbrugge and Sevak, 2002); that is, to relocate to a person to a place where more intensive caring assistance for ADLs can be provided. Therefore, this study also explored whether, in the opinion of informal carers, their relative with dementia's use of ATs at home contributed to or delayed the care home relocation decision. To enable full exploration of institutionalisation decisions, the reasons why people may prefer to remain living at home are considered below.

5.3: Reasons why people with dementia may want to remain at home

In this thesis, remaining at home refers to living in a non-healthcare, community setting with appropriate services if necessary, such as human and technological assistance (Cheek et al., 2005). Living in the community may mean living in: the person's own home, the home of family members, in sheltered housing, or in other warden-based schemes. It includes persons who receive formal care services in these locations. In this section, reasons are presented as to why remaining in one's home may be perceived by the general public, people with dementia, and informal carers as their preferred location of care. The preferred location of care may be in the community because: the home environment could be manipulated and controlled to support ADL performance adequately; the care-recipient may have a strong psychological connection to their home and desire to maintain social connections; and because perceptions of what being in a care home might mean for the resident's future may cause resistance to relocation. These three reasons are considered below.

For this research, one of the most salient reasons people with dementia may want to remain in the community is that they perceive institutionalisation to be unnecessary if they are able to adapt their home environment to manage their ADL disability (Corcoran and Gitlin, 1991). Adapting the home may reduce the environmental-press the person experiences. Environmental-press is the phenomenon in the disablement process whereby the physical environment contributes to the disability experienced because it does not change in accordance with the person's increasing functional limitations (Lawton and Nahemow, 1973, Lawton, 1982). Adapting the home appropriately can reduce environmental-press and optimise ADL performance (Corcoran and Gitlin, 1991). For example, adaptations such as leaving the bathroom door open and relevant ATs such as room signs, memo-minders, and a calendar may help a person with dementia improve their disorientation when locating the toilet, thus aiding continence ADL. Environmental adaptations and aids to support physical impairments could include setting up furniture in strategic places to aid balance and mobility, or ATs such as a raised toilet seat.

A second reason people may wish to remain in the community is their psychological connection to their own home (Slater, 1995). Older adults' preference to live at home may remain even if the environment becomes unsafe (Hagen et al., 2004, Nugent et al., 2007) because they want to conduct ADLs in comfort, privacy, and security. Further, people may prefer to stay living in their own space because they perceive their home and possessions to represent their identity and accomplishments (Krothe, 1997, Kontos, 1998). Living at home has been shown to contribute positively to a person's

sense of autonomy and to help them to maintain their social network (Aminzadeh et al., 2010). Losing one's possessions, social network, independence, identity, and privacy often invokes fear (Aminzadeh et al., 2010). Hence, the prospect of moving to a care home may be frightening because it is perceived to be linked to different types of loss.

The perception of what being in a care home might mean for the person with dementia's future can contribute to the desire to remain living at home (Tinker et al., 2013). There are high rates of depression and mortality among care home residents (Abrams et al., 2016). It is well documented that institutionalised people with dementia have longer acute illness recovery times and are in poorer health than those who remain in the community (Krothe, 1997). However, it is also the case that people with dementia who enter a care home are usually those with greatest physical and cognitive impairments (Bharucha et al., 2004). They are also those with the greatest levels of disability as their dementia and co-morbidities progress over time (Helvik et al., 2014). Thus, it is not surprising that mortality and morbidity among this group is higher, if care home residents are among the oldest and frailest in the population (Davies et al., 2011). However, the poor outcomes of care home residents have been hypothesised to be further affected by care home staff over-estimating frailty and so over-caring for residents, subsequently leading to premature loss of ADL ability (Beck et al., 1997). Being assisted completely can contribute to a care-recipient's sense of learned helplessness; if they no longer do anything for themselves they may eventually identify with their 'sick role', and increase their reliance on others (Faulkner, 2001).

As some people may be frightened of the prospect of care home life, the desire to remain living at home may be a motivating factor for using ATs which could prevent or delay the relocation of care (Mahmood et al., 2008). Indeed, the perception that a device could keep a person at home for longer has been found to be a good predictor of AT use in a cognitively-healthy population (McCreadie and Tinker, 2005). Research question 4 of this study explores whether use of ATs contributes to a decision concerning the relocation of care. Empirical evidence identifying common triggers of institutionalisation among people with dementia is discussed below.

5.4: Triggers for institutionalisation

Although there is a wide body of literature on the institutionalisation of older adults in general (for example, Grundy and Jitlal, 2007), this section presents empirical evidence on relocation triggers solely among people with a clinical diagnosis of dementia. It is estimated that 27% of people with

dementia aged 65-74 years old reside in care homes, this figure rises to 61% of people aged 90 years and older with dementia (Knapp and Prince, 2007). Currently, there are 18,255 care homes in the UK providing 459,488 beds (almost three times the number of hospital beds) (Davies et al., 2011), and it is estimated that at least two-thirds of these are occupied by people with dementia (Alzheimer's Society, 2014c). It is important to identify how people with dementia transitioned into care homes in order to understand the role of ATs in delaying or preventing the relocation of care. The scoping review of literature identified significant predictors for institutionalisation among people with dementia, the four most commonly identified were: the level of ADL disability of the person with dementia; the care-recipient's socio-demographic circumstances; characteristics of informal carers; and receipt of formal care. Each of these is discussed in more detail below.

First, and most crucially for this research, evidence demonstrated that people with dementia's difficulties performing ADLs, and the lack of associated support, was significantly associated with institutionalisation (Luppa et al., 2008). There was strong evidence to suggest that the more severe the dementia symptoms the more likely the relocation (Luppa et al., 2012a, Young, 2009, Strain et al., 2003). However, Juva et al. (1997) found that ADL disability was a more salient factor in relocation than memory impairment alone. Juva et al. (1997) demonstrated that among people with dementia, an inability to complete even one ADL was associated with living in a care home. Other research has indicated that when people with dementia received assistance from others for bathing, toileting, and feeding activities (Gaugler et al., 2003, Gaugler et al., 2007, Luppa et al., 2012b, Young, 2009); had meals-on-wheels (Luppa et al., 2012a); and used an AT for immobility such as a scooter, walker, or cane (Luppa et al., 2012a, Luppa et al., 2012b, Young, 2009), these factors were all significant predictors for moving to a care home (Gaugler et al., 2009b, Horgas and Abowd, 2004, Luppa et al., 2012b, Wackerbarth and Johnson, 1999, Wherton and Monk, 2008). In summary, the research evidence suggests that the presence of ADL disablement can lead to a relocation, and moreover has greater influence than the presence of cognitive impairment alone (Nagi, 1965, Verbrugge and Jette, 1994). This warrants further investigation to explore the specific causes of an ADL difficulty and its link to the reason for the relocation. For example, consider the ADL of feeding. Research indicates that poor nutritional status is strongly predictive of institutionalisation among people with dementia (Zekry et al., 2009). Yet, malnutrition may be the result of any of the following three factors: the person may have been too physically frail to prepare food; unable to (cognitively) perceive that they were hungry; or had an environment (kitchen) that did not meet their needs. Any one of these factors, or a combination of these, could have contributed to the malnutrition. Without investigating the determinants of the ADL difficulties, appropriate care and AT services are difficult

to provide. For instance, a formal carer could have been deployed to prepare food, a cognitive orthotic AT could have prompted for mealtimes, or the kitchen could have been modified with glass-fronted cupboards. Furthermore, there is mixed evidence in the research literature about the link between levels of disability and institutionalisation. Wattmo et al. (2011) found that only IADL disability was related to relocation among people with dementia, and not baseline ADL disability nor change in ADL disability. Coelho et al. (2007) found that ADL disability of people with dementia predicted the timing of relocation but not the event itself. More exploration in this field is required.

A second key group of institutionalisation triggers related to the socio-demographic circumstances of the care-recipient. Living alone, being older, female, single or widowed, and having poor social support were positively related to care home placement among people with dementia (Bharucha et al., 2004, Luppá et al., 2012a, Luppá et al., 2012b, Young, 2009). Having more children was inversely linked to institutionalisation; this is most likely because children can share caring responsibilities (Drame et al., 2011). These findings demonstrate that external contextual factors are as important as the care-recipient's bodily traits for investigating institutionalisation.

The third salient group of triggers related to the characteristics of informal carers of people with dementia. Evidence suggested that carer 'type' may be an important predictor of care relocation, such as being a new carer (Gaugler et al., 2005) or an adult child rather than a spouse (de Vugt et al., 2005). Other research demonstrated that informal carers' negative emotional reactions to the behaviours of their family members with dementia were significantly predictive of institutionalisation (de Vugt et al., 2005, Gaugler et al., 2009b). The behaviours that may be displayed by some people with dementia such as getting lost, paranoia, and aggression can lead to carer stress (de Vugt et al., 2005). Other negative emotional reactions of carers indicated in the scoping review as institutionalisation triggers included: role captivity, depression, and desire to institutionalise (Alspaugh et al., 1999, Gaugler et al., 2000, Gaugler et al., 2009b). The significance of role captivity, that is, feeling trapped by one's caring obligations, as a predictor was investigated by Gaugler et al. (2000) and measured by statements relating to the involuntary aspects of caring such as 'I feel like I have no choice but to provide care'. Results showed that when other family members provided overnight help and assisted with ADLs to give the informal carer some respite, the person was less likely to be institutionalised. Depression was another carer characteristic related to institutionalisation, although it may be indirectly linked through feelings of captivity (Alspaugh et al., 1999). Although interventions to address carers' depression reduced their sense of task demand and overload, the evidence suggested that feelings of captivity were resistant to change and were

sometimes only reduced after institutionalisation occurred (Aneshensel et al., 1993). A mixed-method study by Cohen-Mansfield and Wirtz (2009) demonstrated that institutionalisation was partly predicted by carers' depressed affect in the questionnaire component of their research. Yet, depressive feelings were not mentioned by the carers themselves during interviews. Other research on carer characteristics showed that the desire to institutionalise a relative was significantly predictive of care relocation (Gaugler et al., 2009b). The desire to institutionalise was itself associated with: carers' depression and stress (Gallagher et al., 2011, Spitznagel et al., 2006); non-spousal status (Gallagher et al., 2011); greater knowledge of dementia and low social support (Spitznagel et al., 2006); and a poor quality pre-dementia relationship between the carer and care-recipient (Juva et al., 1997, Winter et al., 2011). For these studies, ADL disability had a weaker influence on the desire to institutionalise in comparison to carer and family characteristics. This finding could be considered encouraging as some of the negative effects of these characteristics may be improved with targeted therapeutic interventions. However, these studies were focused on desire and intentions only, and not the mechanisms of how such desires translate into behaviour (actual institutionalisation). That is, a *desire* to institutionalise may not necessarily lead to a relocation decision (Webb and Sheeran, 2006).

The fourth predictive topic for relocation of care concerned the receipt of formal care services. In Chapter 3 it was discussed that at-home formal care services could prevent or delay institutionalisation (Zarit et al., 1999). However, other research demonstrated that the presence of formal carers was significantly related to institutionalisation (Habermann et al., 2009). It may be that receiving assistance from formal care services indicates that people with dementia are already experiencing such significant functional decline they will inevitably eventually become too impaired for informal and formal community-based care. More research is needed on this.

5.4.1: Gap in knowledge concerning the role of ATs in institutionalisation triggers and decisions

The scoping review identified four topics of significant predictors of institutionalisation among people with dementia, presented above. Yet, none of the studies presented above captured the role of ATs used by people with dementia to perform ADLs. Although some research demonstrated that devices used to support poor mobility (scooter, walker, cane) predicted relocation (Luppa et al., 2012a, Luppa et al., 2012b, Young, 2009), none focused on ATs for the ADLs under investigation in this thesis. Yet, device use may: predict institutionalisation, as the mobility-related ATs above did; make no contribution at all to a relocation of care; or prevent or negate a decision to move. To understand the phenomenon of institutionalisation and how ATs may contribute, more information

is needed on how relocation decisions are made. For example, if the decision to institutionalise typically lies with the family (Gaugler et al., 2003), the question remains as to which trigger made the family begin to discuss potential care relocation. Retrospective evidence is also needed to outline who made the decision and when, the factors that were taken into consideration during discussions, and whether other options were considered to keep the person living at home. There is a possibility that the use or non-use of ATs has more effect on decision-making than current evidence indicates. Some research has aimed to investigate the underlying reasons for a decision and experiences of making it.

5.5: Decision-making for institutionalisation

The quantitative data identifying the triggers for institutionalisation discussed above do not allow a deeper exploration of the experience of making a decision to relocate care. Furthermore, the triggers do not make the institutionalisation decision: humans do (Krull, 2013). In this section, the legal framework governing who can make an institutionalisation decision with or for a person with dementia is presented, followed by the contribution of health professionals. Then, a decision-making model that illustrates why, and when, such a decision may occur is presented (Caron et al., 2006).

5.5.1: The legal framework

People with dementia may be unlikely to make a decision to relocate to an institution themselves, as cognitive impairments can affect the ability of an individual to appropriately assess their lives in relation to ADL performance and safety at home. As such, others may need to act in their best interests to make a decision for them. Under English law all attempts to enable a person to make a decision for themselves must first be made according to the Mental Capacity Act (2005) (MCA) (UK Parliament, 2005) which was first introduced in Chapter 2. The MCA provides guidelines to enable vulnerable adults, which includes people with dementia, to make decisions for themselves wherever possible. The MCA also provides guidance on how others can make a decision on behalf of the individual with dementia if it is assessed that a person lacks capacity to make a decision for themselves. More explanation about the legal decision-making process for research is provided in Chapter 7, as participants with a clinical diagnosis of dementia were partly involved in the data collection for this study. For institutionalisation, if a person with dementia is assessed as lacking the capacity to make such a decision, someone who has registered Lasting Power of Attorney (LPA) status for them can decide in the person's best interests.

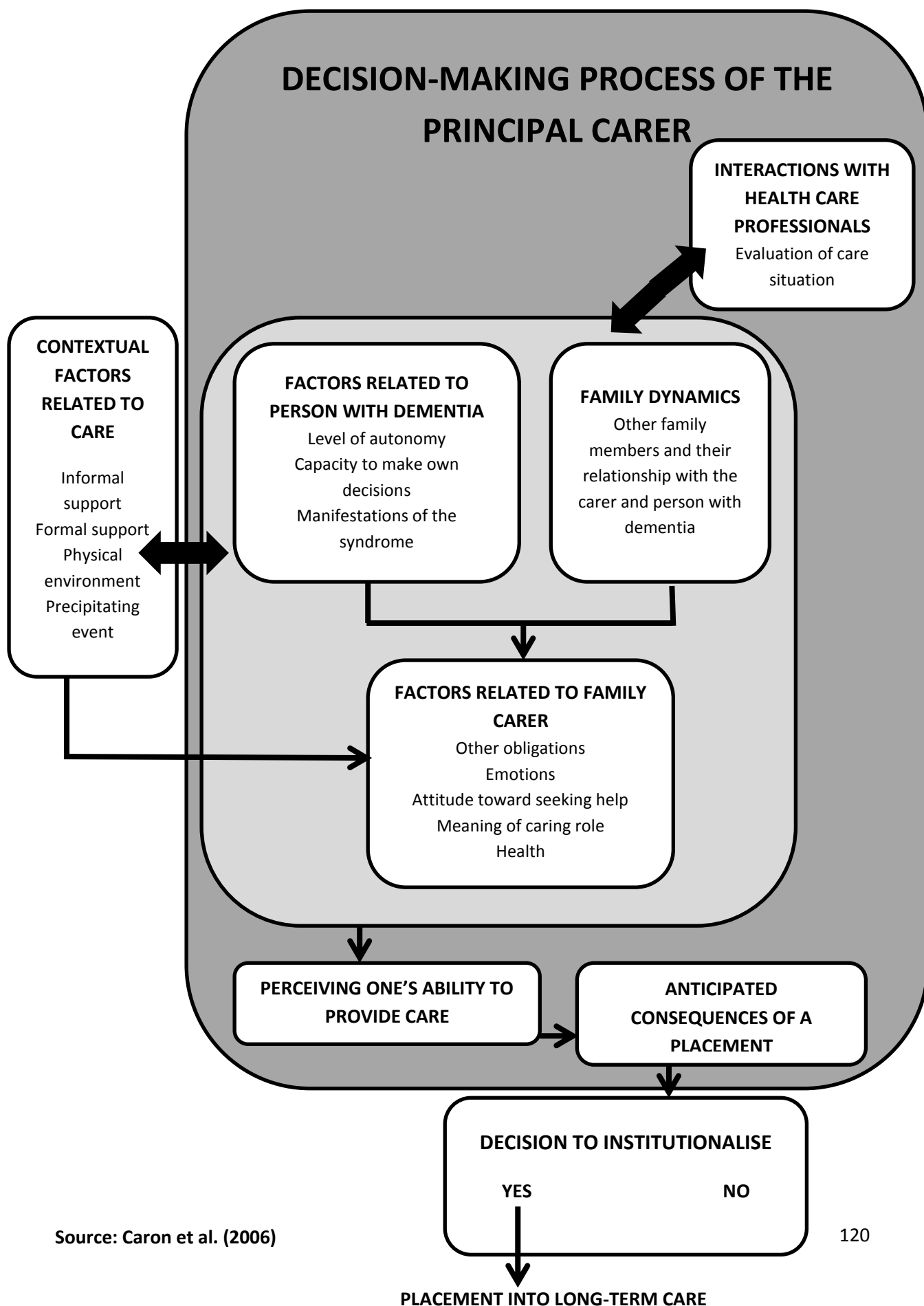
5.5.2: The contribution of health professionals and families

Historically, relocation decisions were often made by the medical professionals involved in the person's care, but evidence demonstrated that adults preferred a family member to make such a decision on their behalf were they to become incapable of deciding for themselves (Menne et al., 2008). This shift from a paternalistic model to person-centred decision-making is considered the best solution when the individual cannot decide for him or herself (Caron et al., 2005). Yet, the initial suggestion of institutionalisation may still be made by a health or social care professional. Family members may lack the confidence to oppose the professional's view and as such, conflicts between their preferences can sometimes arise (Burke, 2010, St-Amant et al., 2012). However, little research was found in the scoping review on who typically makes a relocation decision with or for people with dementia. More evidence on this issue is required, and was captured during this study.

5.5.3: A decision-making model

As well as who makes a relocation decision, how the decision is made has been explored. Canadian researchers Caron et al. (2006) devised a theoretical model of the decision-making process for institutionalisation among people with dementia. Figure 6 below presents their decision-making model, which concerns four categories of factors for consideration. The first category acknowledges the abilities, disabilities, self-governance, and decision-making capacity of the person with dementia (Caron et al., 2006). The second set of factors relate to the informal carer and their perception whether they are able to provide quality care for their relative (Caron et al., 2006). For example, the need for the decision may arise only once it is perceived that the care-recipient requires more intensive ADL assistance than the carer can provide (Boger et al., 2006, Mihailidis et al., 2008). Therefore, it may be the carer's ability to cope with these issues at home, rather than the issue itself, that determines the move to a care home (Habermann et al., 2009).

Figure 6: Decision-making model for the institutionalisation of people with dementia



Source: Caron et al. (2006)

The third set of decision-making factors in Figure 6 relate to the context of care, including informal and formal support, and the physical and non-physical environment. This also concerns the presence of a precipitating event which may rapidly alter the situation and means that the decision cannot be made gradually in response to the person's disablement. To illustrate, a cerebrovascular accident (a stroke) may leave the person with dementia with instant and significant additional functional limitations. The person with dementia becomes more unable to participate in a potential decision, and the carer may perceive that he or she does not possess the specialised caring skills required to support their relative's daily needs. Relocation and its timing may also be dependent upon contextual factors outside of the caring dyad's control; for example, care home waiting lists or the availability of home-based formal care (St-Amant et al., 2012). The fourth category of factors in the model concerns the influence of health professionals in triggering a conversation about institutionalisation; this was discussed previously in sub-section 5.5.2.

Yet, although Caron et al.'s (2006) model demonstrates that a relocation decision can be complex, no empirical evidence of applications of this model could be found in published literature. Caron et al. (2006) were commended for including the perspectives of the care-recipient, but criticised for excluding the Canadian legal context concerning decision-making with and for people with dementia (Taghizadeh Larsson and Österholm, 2014). In this research project, the extent to which the decision-making factors in Caron et al.'s (2006) model applied to people with dementia and informal carers in an English context were explored.

Caron et al.'s (2006) model is unique in its field as it acknowledges the physical environment surrounding the person, such as the design and layout of the person's home, to influence institutionalisation decisions (Lord et al., 2015). However, Caron et al. (2006) did not directly or specifically refer to the contributory role of ATs. Indeed, none of the reviewed literature noted above examined whether carers perceived that ATs delayed or contributed to a relocation decision. There has been, however, some evidence to suggest that telecare and sensor ATs for safety (Woolham and Frisby, 2002), and 'accommodation changes' (non-specified assistive devices and environmental modifications) (Spruytte et al., 2001) could act to delay or prevent institutionalisation for people with dementia. More data on the circumstances that may lead people with dementia to live in a 24-hour care facility are required; in particular, the role that ATs used to manage underlying and ADL disability, and associated residual disability, play in this decision.

Not only are decisions multi-faceted as demonstrated by the decision-making model (Caron et al., 2006), but they can also be emotional for all involved (Wolfs et al., 2012). Care home placement is usually considered a last resort, and the decision itself could be made after months of deliberation and guilt (Wackerbarth and Johnson, 1999). Family members may have difficulty accepting that their community-based care is no longer the best option for their relative. Although difficult, this is a person-centred decision if keeping their relative with dementia at home may inadvertently lead to poorer care (McClendon et al., 2006). Yet despite this, staying in an unsuitable home environment is sometimes perceived as the 'better' situation compared to residing in a care home. The reasons why some people may prefer to remain living at home were discussed earlier in section 5.3 and included: the potentiality of ATs and environmental modifications to transform their house appropriately; the psychological connection to the home; and fear of what living in a care home may mean in relation to morbidity and mortality. Yet, there are many reasons why residing in a care home may be the best location for a person with dementia. These potential benefits follow the presentation of reviewed literature for the fifth topic.

5.6: Presentation of reviewed literature for topic 5

Sections 5.7 and 5.8 of Chapter 5 cover the scoping review of literature for the fifth topic: ATs used by and with people with dementia in care home settings, and the contribution of AT use to connections between residents, staff, and families. Section 5.7 presents the second side of the debate for people with dementia preferring to live at home (section 5.3) compared to the benefits of living in a care home. Only peer-reviewed academic papers were referenced in this section, but not all were dementia-specific. Like all papers referenced throughout this scoping review, all were included based on their relevance to the discussion. An older paper was included because it linked to the earlier-referenced environmental-pressure theory.

In section 5.8, the discussion continues with the role of families in care home life. Papers for this theme focused on empirical research evidence and were chosen for relevance, but not all were conducted specifically on populations with dementia. Overall, the critical appraisal for this topic identified a key knowledge gap; no information on when and how ATs are used for ADLs in care homes for people with dementia including the extent to which they contribute to relationships between residents and carers were sourced. Furthermore, the voice of formal carers on care home life, ADL performance of residents with dementia, and associated AT use, was noticeably lacking. Hence, research question 5 and associated interview questions were created.

5.7: Benefits of living in a care home

In this section, the reasons why care home life may be beneficial for some people with dementia in comparison to living in the community are presented. These reasons concern: the provision of more dignified, intensive, and safe ADL assistance than can be provided at home; the erosion of the person with dementia's psychological connection to their own home; and the unmet social needs of people living in the community. Each reason is discussed in more detail below.

The potential benefits of the performance of ADLs in a care home are threefold. First, receiving and providing assistance at home with particular personal tasks such as toileting can cause embarrassment or distress to the care-recipient and the informal carer (Mihailidis and Fernie, 2002, Mihailidis et al., 2000). The receipt of formal assistance for toileting and other private activities from care home staff may enhance the dignity of the person with dementia and their relationship with their family. The second benefit is that the person with dementia may be able to receive more intensive attention for ADLs in care home settings than at home (Zimmerman and Sloane, 1999). Care tasks can be shared by multiple formal carers over extended periods, along with human and technological monitoring. Staff members are usually less emotionally-invested, thus reducing the likelihood of experiencing the stress that can be experienced by informal carers (Zimmerman and Sloane, 1999). Third, care homes can provide safe locations in which ADL assistance can be given, and are sometimes safer than the person's home given that it may have dementia-friendly design (Day et al., 2000). For example, care home bathrooms can be large to accommodate wheelchairs, multiple bodies, stand-aid hoists, and hand-rails. A care home dining room may be designed to reduce sensory over-stimulation and keep the focus on eating food (Day et al., 2000), thus reducing the likelihood of malnutrition. Appropriate care home design can reduce the risk of falls and life-threatening injuries or conditions (Aminzadeh et al., 2009).

A person's own home can also become less safe as their physical or cognitive functioning progresses and ADL disability increases; this then changes the meaning of 'home' (Dyck et al., 2005, Phillips et al., 2011). If people become immobile, afraid of falling, or fear getting lost and thus infrequently leave their home, they may feel trapped. Their house then represents to a lesser extent their identity and more overtly reflects their disability, and physical or emotional loss (Bailey and Sheehan, 2009). Aminzadeh et al. (2010) interviewed 16 people with dementia within the two month period prior to institutionalisation to explore the sense that they made of living at home

when it could no longer support their needs. Initially, conducting ADLs at home were meaningful exercises which enabled the study participants to express functional competence. By the point of relocation, living at home was paradoxical (Aminzadeh et al., 2010). On the one hand, the home provided comfort, helped them to psychologically cope with their impairments, and contributed to their well-being (Aminzadeh et al., 2010). On the other hand, because of increasing negative experiences linked to their home, such as widowhood and increased ADL disability, the 'home' became a 'house': a site linked to dependency and decline (Aminzadeh et al., 2010). This reduction in emotional connection to the home may be because the environmental-pressure became too much for participants (Lawton, 1982). They did not (or could not) alter their home significantly enough to meet their ADL needs.

Similarly, remaining at home can lead to unmet social needs. Miranda-Castillo et al. (2010) interviewed 152 community-residing people with dementia in the UK and demonstrated how isolation impacted negatively on their quality of life. Having a non-spousal carer, a lack of companionship, and no community networks contributed to these unmet social needs. Yet, care homes have the potential to provide a new 'home'. Where 'home' is, and what it means is dependent on personal subjective criteria that can be transferred between locations (Aminzadeh et al., 2010). The new setting could be more supportive to the person's ADL needs, enabling them to devote more time to social and leisure activities and enhancing well-being (Gitlin, 2003, Golant, 2003). Thus, living in a care home may provide more social support than living in the 'community' but in isolation. Indeed, care homes can provide a new community for residents. Each person's experience of a relocation will differ; a new location does not mean that the person cannot immediately feel a sense of belonging or of 'home' (Phillips et al., 2011). Missing from the literature was whether people with dementia ever brought their ATs for ADLs with them from community to the care home, and subsequently whether ATs contributed to a sense of home in the new location.

To summarise, a move to a care home may be a positive experience (Burke, 2010). Care home residents are as much a part of their own and the wider community than any person living in their own home (Blood, 2013). The following section explores dementia care for ADLs in care home settings, particularly whether informal carers contribute to ADL performance there.

5.8: The role of families in care home life

In this section, studies that investigated the experiences family members of residents with dementia had in care homes and their relationships with managers and staff are presented. The extent to which it is known whether informal carers assist with ADLs in care home settings are also examined. Overall, evidence was limited and more research needs to be conducted in this area.

The experience of permanently relocating to an institution from one's own home can be traumatic for everyone involved (Drame et al., 2011). Perceiving that the care received in a care home is standardised and impersonal can be upsetting for an informal carer who has provided personalised and reactive care to their relative (Litwak et al., 1990). Davies and Nolan (2006) found that monitoring care home workers and ensuring positive interactions with staff, other residents, and other family members were all tactics used by informal carers to establish their new role after a transition. Communication between formal and informal carers is critical to reducing family members' stress and demonstrating that quality, person-centred dementia care is provided (Gaugler et al., 2009a).

Burke (2010) suggested that, after a relocation, the family should be involved in advising and creating care plans as they know the life history, needs, and interests of their relative. The informal carer's experiences and advice should be taken into account by care home staff both when planning care and interpreting the behaviours of a person with dementia. By understanding the individual more holistically, staff are better able to support the resident to maintain their own preferred reality and thereby enhance their well-being (Vittoria, 1998). However, gathering such data from families takes time and commitment which care home staff may not have (Innes, 2009). There has been a call for more research investigating the relationships between family members and institutional care staff (Coehlo et al., 2007). However, no studies were identified in the scoping review of literature which investigated how families and formal carers interact specifically with regards to ADLs and ATs. This knowledge gap was explored in this thesis.

Furthermore, there was little evidence as to what extent ADL assistance was provided by informal carers once in a care home. Gaugler et al. (2004) suggested that informal carers, particularly spouses, of care home residents with dementia felt the need to remain in their caring roles. A study of care home contact by Schulz et al. (2004) showed that almost 50% of spousal carers and 26% of non-spousal carers of people with dementia visited daily. Approximately 54% of these visitors still

provided some kind of physical caring assistance to their relative. However, the authors did not elaborate on the exact nature of this assistance. Yet, physical assistance by families is rarely necessary in care homes unless there is a problem with the quality of care. Wright (2000) interviewed 61 informal carers of older adults, some with dementia, to explore their post-relocation roles. Their main priorities concerned checking quality of care, their relative's safety, and ensuring there were social activities (Wright, 2000). A very small minority, mostly spouses, provided some assistance with ADLs; typically for eating. Furthermore, family carers reported that care home staff had expressed their displeasure at the personal assistance given by families. Ejaz et al. (2002) found that family carers' continued assistance with ADLs, and negative family and care home staff relationships, were predictive of carers' perceived need for significant improvements within the care home.

Overall, research is limited on the extent to which families of care home residents assist with caring tasks and their reasons for doing so. Some evidence suggests that care home staff are reluctant to allow family carers to contribute to care (Davies and Nolan, 2006). Further investigation is needed on the extent to which family carers assist in ADL activity in care homes for their relative with dementia, and what their relationships with formal staff are. Therefore, whether carers contribute to ADL performance in care homes was explored in this research. This included whether they used ATs. It also explored gaps in knowledge arising from Davies and Nolan's (2006) work, who while writing extensively on the contribution of staff to enabling family members to continue caring in care home locations, did not discuss staff with informal carers, nor interview such staff for their opinions on this matter.

5.8.1: Little evidence of perceptions of AT use among care home staff, and staff-family connections

To date, no articles have examined the use of ATs for ADLs by people with dementia in institutional settings. In addition, there are a lack of studies on dementia care that have investigated the perceptions of formal care staff about their activities in care homes (Innes, 2009). In the most relevant study, Stockwell-Smith et al. (2011) interviewed 35 care staff of dementia units to investigate their perceptions of their roles. The findings provided insight into how some formal carers use negative language to discuss residents with dementia; for example, they spoke about residents as if they had no identity beyond their diagnosis. Although their study did not concern how ADLs were conducted or whether ATs were used, it nevertheless highlighted that research on formal care home staff may be important when understanding living well with dementia while residing in a care home. Only one article in the reviewed literature investigated social care professionals' views of

a particular AT; Nygård (2009) conducted focus groups with professionals who provided stove timers to older adults. They perceived them as a fire safety technology rather than as disability-related AT for the IADL of food preparation. The professionals saw no need for a follow-up appointment to ensure the receiver understood how to use the technology and re-evaluate its appropriateness. This suggests that professionals may have alternative perceptions of the role that ATs have in service-users' daily lives compared to the academic community, people with dementia, or informal carers. Furthermore, as challenging behaviours and ADL disability of people with dementia were both significantly associated with formal carers' stress (Miyamoto et al., 2010), the role that ATs could play in assisting formal carers as well as informal carers in their tasks was investigated in this research.

5.9: Chapter 5 summary

In this chapter, the significance of human or technological support to assist ADL performance was related to a common outcome for older adults: relocation to a care home. The modified disablement process discussed in Chapter 3 acknowledged that the presence of carers and ATs may only slow the progression of disability, in this chapter the difficulties that may remain were introduced as residual disability. Residual ADL disability has been shown to significantly predict institutionalisation, although other potential triggers include the characteristics of informal carers, the relationship between the caring dyad, the physical environment, and other contextual considerations. These factors were also all shown to qualitatively contribute to decision-making. However, almost all of the reviewed research was observed to lack specific consideration of the role ATs may play in leading to or delaying the relocation of care. Another knowledge gap in understanding AT use for ADLs concerned the use of devices in care homes. It is not known the extent to which technological support is given in such locations; whether informal carers like to continue providing support for ADLs once their relative is in a care home; or the perceptions that formal care home staff have on the role of ATs in institutional dementia care.

The multiple gaps in knowledge identified throughout Chapters 3, 4 and 5 were acknowledged and were addressed in the study aim and five research questions presented in Chapter 1. A mixed-methods study was then designed to address these. The first objective was to analyse a large, nationally-representative dataset to examine the relationship between poor cognition, ADL disability, and use of technologies. The methods and results of these analyses are presented in the following chapter.

Chapter 6: Quantitative exploration of low cognition and use of mobility-related ATs

In this chapter, results are presented from statistical analyses of the relationship between the use of mobility-related ATs and cognition, taking into account ADL and IADL disability, a multitude of doctor-diagnosed health conditions, and socio-demographic factors. The cross-sectional analysis was conducted on data collected for Wave 5 of the English Longitudinal Study of Ageing (ELSA) dataset. The ELSA is a large-scale, nationally-representative survey of people aged 50 years and older residing in private households throughout England. The findings were intended to contribute knowledge to the exploration of research question 2 of this study to investigate the types of ATs used by people with dementia, and a key gap in knowledge identified in Chapter 4 concerning which ATs are currently used in community settings.

This chapter begins with the presentation of background research evidence and subsequent design of the analysis. The initial research aim was modified because there were few participants with dementia in the dataset, and limited information on types of ATs collected in ELSA. Thus, the investigations focused on the relationship between low cognitive function and the use of ATs designed to support difficulties with mobility. The dataset that was used is then described, and the analytical sample defined. This is followed by a discussion of the variables used in the analysis, including the outcome variable representing the use of mobility-related ATs, and the key independent variable of interest: cognitive function score. The tests used to analyse associations between all variables are then described.

The results of the statistical analyses are then presented. First, the prevalence of mobility-related ATs is described, followed by the distribution of the overall cognitive function score of participants. Second, bivariate associations between the use of mobility-related ATs and all independent variables are discussed: cognition, disability, health, and socio-demographics. Third, a logistic regression model was used to examine whether the use of mobility-related ATs was significantly associated with cognition once the other key characteristics were taken into account. The strengths of the findings are then discussed, and the limitations acknowledged.

6.1: Background and design

The initial aim of this analysis was to examine the association between dementia and ATs used for the performance of ADLs in a nationally-representative English population. Specifically, the objective

was to investigate this relationship while taking disability, other doctor-diagnosed health conditions (co-morbidities), and socio-demographic variables into account. These variables were included since previous work has shown that disability and health factors are significantly associated with the use of ATs among a cognitively-healthy but physically-frail population (Wielandt et al., 2006). The disablement process model introduced in Chapter 3 demonstrated how cognitive and physical impairments, caused by multiple co-morbidities including dementia, lead to functional limitations which in turn impact upon performance of ADLs (Nagi, 1965, Nagi, 1991, Verbrugge and Jette, 1994). The poorer health a person has the more ATs they own and use, and indeed people with dementia are certainly users of ATs (Mann et al., 1992, Mann et al., 1993). However, some research suggests that people with cognitive impairment only (measured by scoring 24 or fewer on the Mini-Mental State Examination) are less likely to use ATs compared to physically-frail but cognitively-healthy populations (Mann et al., 1993). Yet, those individuals with both cognitive and physical functional limitations were almost as likely to use ATs as the people who had only physical issues (Mann et al., 1993). Thus, the impact of co-morbid health conditions on the use of technologies required exploration. Further, Mann et al.'s (1993) research was conducted on data collected from a non-representative population within the USA, so an investigation on nationally-representative English data was needed in order to make a useful contribution to dementia and AT policies, services, and procedures.

The initial aim of the statistical analysis was to investigate the relationship between dementia and ATs used for ADLs. However, preliminary analysis of the Wave 5 ELSA dataset revealed too few respondents with dementia to permit detailed and powerful analysis; only 38 of the analytical sample of 5,012 participants (0.8%) reported having a clinical diagnosis. Given this limitation, the investigation instead used respondents' overall cognitive function score. This was calculated by summing their responses to assessments across three cognitive domains. How this and all variables were calculated and coded is described below in sections 6.4 and 6.5. Previous work has shown that low cognitive function is significantly associated with onset of ADL disability (Spiers et al., 2005). Similar to evidence on people with diagnosed dementia, people with low cognitive function are less likely to use ATs and more likely to use human carers than cognitively-healthy people due to complexities of managing devices (Agree et al., 2004, Mann et al., 1993, Verbrugge and Sevak, 2002). Only about 70% of devices that are owned by people with low cognition are used, compared to 83% of the devices owned by people with physical-impairments only (Mann et al., 1993). Therefore, the aim of the analysis was to explore the relationship between cognitive function (low to high) and the use of ATs.

However, data on all potential ATs for ADLs was not collected in ELSA. Participants were only asked whether they used any of eight devices: a cane or walking stick; a walking frame or walker; a manual wheelchair; an electric wheelchair; a scooter; an eating utensil; a personal alarm; and elbow crutches. Only one of these ATs was related directly to an ADL: the eating utensil. The personal alarm was a telecare device ensuring safety through communication, and the other six were mobility-related devices. Too few participants used an eating utensil in the analytical sample to attain statistical power, so the revised aim of the analysis was to investigate the relationship between poor cognition and use of one or more of the six mobility-related ATs. According to the disablement process model presented in Chapter 3 (Nagi, 1965, Nagi, 1991, Verbrugge and Jette, 1994), mobility difficulties are physical functional limitations, and thus one type of precursor to ADL related disability (Lawrence and Jette, 1996). As such, mobility-related ATs may be as useful to help the person perform ADLs as for each individual mobility action (Agree and Freedman, 2000). For example, the use of a walking stick could moderate the effects of physical functional limitation during gait, but as a result could help the user to get to the bathroom more quickly and easily than without the stick, thus supporting their performance of toileting and continence ADLs. Moreover, Mann et al. (1992) demonstrated that although their participants with dementia had many different types of ATs in their home, the devices they used most frequently were actually those used for mobility; manual wheelchairs, transfer belts and grab-bars. These were likely used because of the additional co-morbidities their participants experienced; in particular, arthritis. Technologies to help support cognitive limitations only, such as reminder signs, were less frequently used. Still, Agree et al. (2005) showed that people with dementia were more likely to use human carers to assist with mobility, compared to cognitively-healthy matches who were more likely to use mobility-related ATs. Thus, an investigation of the association between cognitive status and mobility-related AT use was warranted.

The research hypothesis was that cognitive function would be significantly associated with the use of mobility-related ATs. It was also hypothesised that ADL and IADL disability and doctor-diagnosed health conditions would be significantly associated with mobility-related AT use. This analysis is expected to increase understanding of the key factors associated with the use of mobility-related ATs by older adults, whom are those in the population most likely to experience cognitive and physical co-morbidities (Dunlop et al., 2002).

6.2: The ELSA dataset

The ELSA is a nationally-representative, longitudinal study originally conducted on approximately 12,000 adults recruited from the research population of the Household Survey for England in 1998, 1999, and 2000. It has a sample of respondents aged 50 years and older (and their partners) living in private households in England (Steptoe et al., 2013). The main purpose of ELSA is to provide information on the ageing population of England, and to enable researchers to explore changes in their lives over time. Information is gathered on: health and biomarkers, housing, work, retirement, pensions, cultural and social activities, among a variety of other measures (Marmot et al., 2014). Data are collected in face-to-face computer-assisted interviews and self-completion questionnaires (Steptoe et al., 2013). The respondents provide written, informed consent for their participation; ethical approval was received from the Multicentre Research and Ethics Committee (Steptoe et al., 2013). Datasets, accompanying user guides, technical reports, dictionaries and other supporting information are freely accessible to researchers (The Institute for Fiscal Studies, 2011b, Steptoe et al., 2013).

Participants in ELSA provide responses every two years. These are known as Waves. Information presented in Appendix 3 details the years that data were collected for each Wave, and the number of participants in the final corresponding dataset. In some Waves, respondents were required to provide additional data during a nurse visit, life history module, or risk module. Refreshment samples of participants were recruited in Waves 3, 4 and 6; again sourced from Household Survey for England cohorts. This was to boost the sample since drop-out occurred between Waves, and to collect data from new people who had become eligible in recent years; for example, they had reached 50 years of age. Appendix 3 includes the fieldwork individual response rate for each cohort per Wave. These response rates were calculated by dividing the total number of individuals with an interview by the total number of individuals eligible for that Wave. Each percentage was sourced from the Wave technical reports (e.g. Bridges et al. 2015). Appendix 3 also lists the ATs respondents were asked about each Wave. Elbow crutches were added to the list of ATs from Wave 2 and onwards. The cross-sectional analyses in this study were conducted using data from the Wave 5 dataset (Marmot et al., 2013), which was the most recently available at the time of analysis.

6.3: Analytical sample

There were 10,274 respondents in Wave 5. The dataset consisted of core-members; people who were randomly selected to participate as long as they were aged 50 years or older and resided in the

community. Data were also collected from core-members' partners, regardless of age, if they resided in the same location.

Five exclusion criteria were applied to the Wave 5 dataset to create the analytical sample for this study. The first was to exclude non-core members. These non-core members were younger or new partners of core members. As they had not been randomly sampled, they were not nationally representative of the population under investigation. Second, respondents who had only a partial interview were excluded as they were missing too much relevant information. Therefore, only the people who completed their interview were selected for investigation. The third criterion excluded respondents who did not reside in a private household, that is, participants who lived in an institution such as a care home or hospital. This was because ELSA data are only representative of individuals who live in private households. For the fourth exclusion criterion, any data elicited from participants with an interview-by-proxy; that is, another individual ('proxy') who answered on the person's behalf, were removed. This was because proxies were not asked to respond to the health questions that were needed for this analysis. Fifth, any respondents under 65 years of age were excluded. This was to keep the analytical sample to older adults, and to follow previous work that used ELSA data on frailty, cognitive health, and aspects of social care (e.g. Gale et al., 2015; Langa et al., 2009; Vlachantoni et al., 2013).

In total, the final analytical sample consisted of 5,012 core-member respondents aged 65 years and older, who resided in the community, and who completed a full interview. There were 2,741 women (55% of the analytical sample). Most participants were in the 65-74 years old age category (58%), 33% were in the 75-84 years old category, and the remaining 9% were aged from 85 years and older.

6.4: Outcome variable

The outcome variable in this analysis was the use of mobility-related ATs. In ELSA, participants were asked to indicate whether they used any of the following: a cane or walking stick, a walking frame or walker, a manual wheelchair, an electric wheelchair, a buggy or scooter, special eating utensils, a personal alarm (which could be used to call for help following a fall), and elbow crutches.

Participants were not asked whether they used any other type of ATs. As was highlighted in section 6.1, with the exception of eating utensils for eating and personal alarms for safety and crisis situations, the ATs captured by ELSA related to mobility difficulties. Therefore, a dichotomous indicator 'Uses mobility-related ATs' was created, categorising respondents into whether or not they

used the six mobility-related ATs: walking stick, walking frame, manual wheelchair, electric wheelchair, buggy or scooter, and elbow crutches. The variable was coded to indicate whether respondents did not use any mobility-related ATs or if they used at least one of them, replicating previous work (Agree et al., 2005).

6.5: Independent variables

The independent variables in this study captured cognitive function, disability, other multiple health conditions, and socio-demographic factors. The key independent variable was overall cognitive function. The Wave 5 dataset and its accompanying dataset of derived variables did not include a derived variable to indicate respondents' total cognitive function. Therefore, one was created using each participant's scores across the three cognitive domains of orientation, immediate recall and delayed recall, replicating Langa et al. (2009). To assess orientation, participants were asked for the current day, date, month, and year. One point was awarded for each correct answer, giving a maximum of four points for total orientation. To test immediate recall, participants were shown a list of 10 words on a computer screen and then asked to recall them immediately. Each correct answer was awarded one point. Delayed word recall was tested by asking the respondent to remember the list of words later in the interview. The maximum score for both the immediate recall and delayed recall tests was 10 points. Total cognitive function score was calculated by summing across the three scores to give each participant a score which ranged from zero to 24 points (Langa et al., 2009). Then, cognitive index quintiles were created from this new variable. Respondents in the lowest quintile were those with the poorest cognitive function. People in the highest quintile had the best cognitive function.

Disability experienced by participants when performing ADLs and IADLs were captured in ELSA. For ADLs, participants were asked to indicate if they ever had difficulty with any of the following activities because of a physical, mental, emotional, or memory problem which had thus far lasted three months or longer: dressing, washing, bathing, difficulty getting in and out of bed, eating, and using the toilet. Following Langa et al. (2009), responses across the six items were grouped into an 'ADL difficulty' variable which was then divided into three categories: 'None', '1-3 ADLs', and '4-6 ADLs'. For IADLs, participants were asked to indicate if they ever had difficulty with any of the following activities for three months or longer: using a map, preparing food, shopping, using the telephone, taking medication, doing housework or gardening, and managing money. Responses to

these items were grouped into an 'IADL difficulty' variable which was further split into three categories: 'None', '1-3 IADLs', and '4-7 IADLs'.

Participants were asked if they had a number of doctor-diagnosed health conditions. As cognitive impairment in older adults is often accompanied by co-morbidities, it is important to take other health factors into account (Dunlop et al., 2002). Furthermore, health conditions have shown to be important predictors of the number of ATs used by people with dementia and low cognitive function (Mann et al., 1992). The health variables used in this analysis were: poor eye health, high blood pressure, stroke, other cardiovascular conditions, diabetes, lung problems, and arthritis. Other conditions that were captured were: incontinence that had lasted more than one month, whether the person had ever fallen and caused themselves a serious injury, and depressive symptoms. To capture depressive symptoms, ELSA used the Centre for Epidemiologic Studies Depression Scale (Devins and Orme, 1985). Consistent with previous literature, a score of four or more depressive symptoms out of a total possible eight points indicated depression (Llewellyn et al., 2008). For some conditions, multiple similar health problems were grouped into one indicator. For example, the eye-health conditions of glaucoma, diabetic eye disease, macular degeneration, and cataracts were merged into a new variable entitled 'Poor eye health'. This measure was coded '0' for 'None of these eye conditions' and 1 for 'Has at least one of these eye conditions'. They were grouped like this because keeping each separate would have resulted in too few respondents with each specific condition to permit meaningful analysis. A table that displays the original variables, and the new indicators created from them, is presented in Appendix 3.

Socio-demographic variables represented the sex, age, and wealth of participants. As indicated in section 6.3, respondents who were under 65 years of age were excluded from the sample. Again following Langa et al. (2009), participants were categorised by age into one of three groups: '65-74 years old', '75-84 years old' and '85-90+ years old'. The final category included 90+ because in ELSA the exact age of participants who were older than 90 years was not disclosed, to prevent identification. A summary financial variable that represented each person's non-pension wealth was split into quintiles. A quintile of 1 represented people with the least wealth. A quintile of 5 represented people with the greatest wealth.

In preliminary analysis, three other health related conditions had been included. These were: whether respondents had ever had joint replacement surgery; whether they had any property adaptations in their home; and their mobility score calculated by summing participants' difficulties in

performing up to 10 mobility tasks. The mobility tasks were: walking 100 yards; sitting for about two hours; getting up from a chair after sitting for long periods; climbing several flights of stairs without resting; climbing one flight of stairs without resting; stooping, kneeling or crouching; reaching or extending his or her arms above shoulder level (either arm); pulling or pushing large objects; lifting or carrying weights over 10lbs; and picking up a 5p coin from a table. However, these three variables were highly correlated with the other key health measures discussed above. They were not included in the final logistic regression model because of potential problems with multi-collinearity.

6.6: Analyses

Analyses were carried out using Statistical Package for the Social Sciences (SPSS) Version 22. First, descriptive and inferential statistics of the sample were explored, using percentage distributions for categorical variables and means and standard deviations for continuous data. Then, bivariate associations using chi-square statistic between the outcome and independent variables were applied. These were appropriate as all of the variables of interest were categorical.

The correlates of mobility-related AT use, and in particular its association with cognition, was then investigated using a logistic regression model. Logistic regression was chosen as the method of analysis given that the outcome variable of interest, use and non-use of mobility-related ATs, was binary. Data were checked prior to running the regression to ensure the ratio of cases to variables had enough responses in every given category (Hosmer Jr and Lemeshow, 2004). As logistic regression assumes multi-collinearity, this was checked for each explanatory variable with an initial multiple regression analysis. No Variance Inflation Factor score was greater than 10 indicating that there was no violation of multi-collinearity. A cross-sectional weight was added to the data to adjust for differences in responses and representation among the sample (NatCen Social Research, 2014).

6.7: Results

In this section, the results from the statistical analyses on the association between the use of mobility-related ATs and cognitive function once the disability, health, and socio-demographic variables were taken into account are presented. First, the distribution of the two key variables: mobility-related AT use and cognitive function, are shown. Second, the results of bivariate analyses between the independent variables and use of mobility-related ATs are presented. Finally, the logistic regression model investigating the association between the outcome and independent variables is displayed.

6.7.1: Distribution of two key variables - mobility-related AT use and cognitive function index

Table 2 displays the distribution of respondents who did and did not use mobility-related ATs. Almost 30% of the sample reported using at least one AT for mobility-related issues. There were no missing data for this variable.

Table 2: Distribution of mobility-related AT use among respondents aged 65 years and older

Use of mobility-related ATs	Frequency: un-weighted N (weighted %)
Does not use mobility-related ATs	3681 (71.3)
Uses at least one mobility-related AT	1331 (28.7)
Total	5012 (100)
Missing	-

In Table 3, the total cognitive function index based on quintiles is shown. As can be seen, the distribution of the quintiles was not evenly 20% of the respondents' scores. This is because many respondents with identical scores and who were on the cusp between two quintiles would have been allocated to only one group. There were 17 respondents with missing data for this indicator.

Table 3: Distribution of total cognitive function index among respondents aged 65 years and older

Cognitive function index	Frequency: un-weighted N (weighted %)
1 (lowest cognitive function score)	892 (20.0)
2	1127 (23.0)
3	1114 (22.0)
4	986 (18.8)
5 (highest cognitive function score)	876 (16.0)
Total	4995 (99.7)
Missing	17 (0.3)

6.7.2: Bivariate results

Table 4 shows the bivariate associations between the independent variables and the outcome variable of interest. The chi-square statistic was used to assess significant relationships between mobility-related AT use and the key characteristics of interest: cognitive function, ADL and IADL disability, health conditions, history of falls with serious injury, sex, age, and wealth.

Table 4: Bivariate associations between independent variables and mobility-related AT use

Variable (un-weighted N)	No use of mobility- related ATs within that condition % (weighted)	Use of mobility- related ATs within that condition % (weighted)	Total % within that condition	χ^2 (df) (weighted)	P (weighted)
Cognitive function index					
1 (lowest) (892)	52.9	47.1	100		
2 (1127)	65.7	34.3	100		
3 (1114)	75.5	24.5	100		
4 (986)	81.4	18.6	100		
5 (highest) (876)	85.1	14.9	100	282.31 (4)	<0.01
Difficulties with ADLs					
None (3852)	83.5	16.5	100		
1-3 ADLs (1032)	36.9	63.1	100		
4-6 ADLs (127)	12.2	87.8	100	1034.72 (2)	<0.01
Difficulties with IADLs					
None (4075)	81.0	19.0	100		
1-3 IADLs (861)	34.8	65.2	100		
4-7 IADLs (75)	17.3	82.7	100	822.51 (2)	<0.01
Poor eye health					
No (4013)	74.7	25.3	100		
Yes (999)	57.9	42.1	100	100.17 (1)	<0.01
High blood pressure					
No (3060)	76.1	23.9	100		
Yes (1935)	64.0	36.0	100	76.70 (1)	<0.01
Had stroke					
No (4748)	73.0	27.0	100		
Yes (262)	42.7	57.3	100	107.22 (1)	<0.01
Has other CVD condition					
No (3100)	75.4	24.6	100		
Yes (1912)	64.7	35.3	100	60.53 (1)	<0.01
Diabetes					
No (4453)	73.3	26.7	100		
Yes (556)	55.8	44.2	100	67.95 (1)	<0.01
Lung disease or asthma					
No (4377)	73.2	26.8	100		
Yes (635)	58.8	41.2	100	52.28 (1)	<0.01
Arthritis					
No (2729)	84.3	15.7	100		
Yes (2060)	55.6	44.4	100	429.49 (1)	<0.01
Incontinence					
No (4427)	74.3	25.7	100		
Yes (583)	49.0	51.0	100	147.46 (1)	<0.01
Depressive symptoms					
0-3 (4234)	75.7	24.3	100		
4-8 (760)	48.8	51.2	100	216.96 (1)	<0.01

Variable (un-weighted N)	No use of mobility- related ATs within that condition % (weighted)	Use of mobility- related ATs within that condition % (weighted)	Total % within that condition	χ^2 (df) (weighted)	P (weighted)
Falls with serious injury					
No (4560)	73.6	26.4	100		
Yes (451)	49.2	50.8	100	111.36 (1)	<0.01
Sex					
Male (2271)	77.0	23.0	100		
Female (2741)	66.6	33.4	100	58.67 (1)	<0.01
Age category					
65-74 (2907)	82.9	17.1	100		
75-84 (1653)	63.8	36.2	100		
85-90+ (452)	38.2	61.8	100	487.13 (2)	<0.01
Wealth index					
1 (lowest) (993)	55.2	44.8	100		
2 (994)	67.3	32.7	100		
3 (993)	74.0	26.0	100		
4 (993)	77.6	22.4	100		
5 (highest) (993)	85.1	14.9	100	229.53 (4)	<0.01

ADLs = Activities of Daily Living, IADLs = Instrumental Activities of Daily Living, CVD = cardiovascular. Percentages rounded to one decimal place. Chi-square and p value rounded to two decimal places. N = 5,012.

The results in Table 4 show that all of the independent variables showed significant associations with use of mobility-related ATs. Concerning cognition, the results showed that the greater a person's cognitive function, the less likely they were to use the ATs. Nearly 15% of participants who were classified into the highest cognitive function quintile used mobility-related ATs compared to approximately 47% of people in the lowest cognitive function quintile. Disability when performing ADLs and IADLs was significantly associated with the use of ATs to assist with immobility. For instance, close to 88% of people who reported problems with performing four to six ADLs used mobility-related ATs, compared to almost 63% of people who reported one to three ADL difficulties, and approximately 17% of people with no ADL difficulty. Similarly, almost 83% of people who reported difficulties with four to seven IADLs used ATs for immobility, compared to approximately 65% of people with difficulty performing one to three IADLs, and 19% of people with no IADL difficulty.

The presence of all health conditions, including incontinence and experiencing injury from a fall, were also significantly associated with the use of mobility-related ATs. The largest association was

having had a stroke; just over 57% of people who reported having a stroke used at least one AT to manage their mobility. This is most likely because a stroke can leave a person with severe physical weakness, causing immobility which may be alleviated with appropriate ATs (Dark and Sander, 2014, Salminen et al., 2009). Results also indicated that female participants, people in the oldest age category, and the poorest respondents were significantly associated with using more mobility-related ATs.

However, Table 4 only indicates the associations between pairs of variables and not how several indicators are associated with the outcome of interest. That is, the aim of this study is to understand the association between low cognition and use of mobility-related ATs, but as poor cognition can be co-morbid with other health conditions it may be that these factors are related to mobility-related AT use and not cognition per se. To illustrate, Table 4 shows that approximately 47% with the poorest cognitive function used mobility-related ATs compared to almost 15% of people with the highest cognitive function. This indicates that people with lower cognitive function were more likely to use these devices. However, it may be that people with the lowest cognitive function were also those reporting the worst physical health, that is, had many co-morbid conditions, which influenced AT use. Another example from Table 4 concerns the finding that approximately 51% of people reporting four to eight depressive symptoms used mobility-related ATs, compared to close to 24% of people with zero to three depressive symptoms. This result may have been influenced by poor cognition function as depression and dementia result in similar symptoms (Landes et al., 2005). Further, when depression and dementia occur co-morbidly they can result in poor cognitive and physical functioning (Greenwald et al., 1989, Kaup et al., 2007, Llewellyn et al., 2008, Singh-Manoux et al., 2010). Moreover, low mood is also likely to be influenced by being in poor health. Thus, it was necessary to explore the independent effect of cognitive function whilst controlling for the other variables. To this end, a logistic regression model analysis was conducted.

6.7.3: Logistic regression model

A logistic regression model was appropriate given the binary nature of the outcome variable. The independent variables of interest were related to: cognitive function, difficulties performing ADLs and IADLs, the various co-morbid conditions, falls with injury, sex, age, and wealth. The aim was to investigate whether poor cognitive function showed a positive association with use of mobility-related ATs once the other independent variables were taken into account.

The correlates were entered into the model in blocks: first the demographic variables of sex, age, and wealth were inputted. Second, cognitive function was added. Third, the health variables were inserted. Fourth and finally, disability with ADLs and IADLs was entered. The odds ratios for the estimated parameters, 95% confidence intervals, and levels of significance for each independent variable in the fourth and final logistic regression model are displayed in Table 5 below. This final model was statistically significant compared to the constant-only model ($\chi^2(25) = 1671.17$, $p < 0.01$).

As can be seen in Table 5, cognitive function continued to show a significant positive association with the use of mobility-related ATs, even when other health conditions and socio-demographic factors were taken into account. Respondents in the lowest cognitive function quintile reported 71% higher odds of mobility-related AT use, and in the second lowest quintile 74% higher odds, compared to those in the highest cognitive quintile, even when controlling for the other independent variables. Holding all of the other variables constant, people with difficulty performing one to three ADLs were 4.15 times more likely to use mobility-related devices in comparison to those with no ADL difficulties. This increased for people with difficulty performing four to six ADLs, who were 8.66 times more likely. The predicted odds for people with difficulty performing one to three IADLs were 2.79 times greater, and for people experiencing difficulty with four to seven IADLs the odds were 3.27 times greater, than the reference category of no IADL difficulty. Some of the health variables showed significance, having: poor eye health (30% higher odds); a stroke (74% higher odds); and diabetes (63% higher odds) were all predictive of the use of mobility-related ATs compared to not having those conditions. The predicted odds for people with arthritis were 2.94 times the odds for people without arthritis. Being incontinent meant that a person was 1.40 times more likely to use mobility-related ATs in comparison to the non-incontinent counterparts. The predicted odds for people who had been seriously injured from a fall in the past were 71% higher than people who had not experienced such trauma. People who displayed four to eight depressive symptoms were 1.38 times more likely to use mobility-related ATs compared to respondents in the reference category of zero to three depressive symptoms.

Table 5 also shows that females reported 23% higher odds than males of using mobility-related ATs. People aged 85 to over 90 years old were 4.7 times more likely to use mobility-related ATs compared to participants of other ages. Using mobility-related ATs was 1.71 times more likely for people in the lowest wealth quintile compared to respondents in the other wealth categories.

Table 5: Multivariate binary logistic regression model of correlates of mobility-related AT use among respondents aged 65 years and older

Variable	Odds ratio	95% Confidence Interval	P
Cognitive function index			
1 (lowest)	1.71	(1.24-2.37)	<0.01
2	1.74	(1.28-2.38)	<0.01
3	1.38	(1.01-1.90)	0.05
4	1.23	(0.88-1.72)	0.22
1-3 ADL difficulties	4.15	(3.42-505)	<0.01
4-6 ADL difficulties	8.66	(4.49-16.69)	<0.01
1-3 IADL difficulties	2.79	(2.26-3.45)	<0.01
4-7 IADL difficulties	3.27	(1.60-6.70)	<0.01
Has poor eye health	1.30	(1.06-1.60)	0.01
Has high blood pressure	1.15	(0.96-1.38)	0.13
Had a stroke	1.74	(1.22-2.48)	<0.01
Has other CVD condition	1.04	(0.87-1.25)	0.65
Has diabetes	1.63	(1.25-2.13)	<0.01
Has lung disease or asthma	1.26	(0.99-1.62)	0.06
Has arthritis	2.94	(2.46-3.51)	<0.01
Has incontinence	1.40	(1.09-1.80)	0.01
4-8 depressive symptoms	1.38	(1.10-1.72)	<0.01
Has had a fall with serious injury	1.71	(1.30-2.24)	<0.01
Female	1.23	(1.02-1.47)	0.03
Age category			
75-84	2.11	(1.74-2.57)	<0.01
85-90+	4.70	(3.57-6.20)	<0.01
Wealth index			
1 (lowest)	1.74	(1.29-2.34)	<0.01
2	1.48	(1.09-2.01)	0.01
3	1.43	(1.06-1.94)	0.02
4	1.18	(0.86-1.61)	0.31
Other outputs of the model			
- 82.0% of the respondents' scores were classified correctly			
- Nagelkerke's R ² : 47.2% relationship between the predictors and the outcome variable			
- Cox and Snell R ² : 32.7% of the variation in the outcome was explained by the model			

ADLs = Activities of Daily Living, IADLs = Instrumental Activities of Daily Living, CVD = cardiovascular. Reference categories: cognitive function index 5 (highest); no ADL difficulties; no IADL difficulties; no eye health conditions; no high blood pressure; no history of stroke; no other CVD conditions; no diabetes; no lung disease or asthma; no arthritis; no incontinence; 0-3 depressive symptoms; no falls with serious injury; male sex; aged 65-74 years old; wealth index 5 (highest). All figures rounded to two decimal places. Significant odds ratios are shown in bold. N = 5,012.

6.8: Strengths of the results

The findings make a contribution to empirical evidence linking statistical associations between low cognition and use of mobility-related ATs. This study was also the first to use ELSA data to examine associations between disability, health, and demographic variables with use of mobility-related ATs, as the only previous ELSA analysis demonstrated that older age and IADL and ADL difficulties predicted the use of personal call alarms (Wave 3 data) (Nyman and Victor, 2014); a link between frailty and AT use (Wave 4 data) (Gale et al., 2015); and that ADL disability and AT use predicted the receipt of social care (Wave 4 data) (Vlachantoni et al., 2013).

The results show that poor cognitive function is positively associated with the use of mobility-related ATs even when the other health, disability, and socio-demographic factors are taken into account. This refutes previous research that indicated people of low cognitive function were less likely to use ATs than people with higher cognition (Agree et al., 2004, Mann et al., 1993, Verbrugge and Sevak, 2002). However, the analysis shows a significant positive association but not a causal link. It may be that cognition per se is associated with mobility-related AT use or, as was discussed in the disablement process in Chapter 3, the pathology of dementia directly leads to physical impairments and physical functional limitations (mobility difficulties) which in turn are related to AT use. Or, it may be that people with lower cognitive function, also being those in poor health, had more contact with health or social care services that in turn provided the technologies to those respondents; more exploration is required here. The evidence also suggests that disability with more ADLs and IADLs was very strongly associated with the use of at least one AT for mobility difficulties. According to the disablement process model, immobility is a functional limitation that leads to difficulty performing the socially-defined ADLs and IADLs (Nagi, 1965, Nagi, 1991). Verbrugge and Jette's (1994) modified disablement process model indicated that extra-individual factors such as ATs could compensate for immobility and prevent ADL disability from occurring, or at least reduce the impact of immobility on disability. However, it would appear from the results that even the use of the one or more of the six mobility-related ATs that were captured could not compensate for ADL and IADL disability.

6.9: Limitations of the analysis

There were several limitations to these analyses and results. First, there were too few ELSA respondents who self-reported with a clinical diagnosis of dementia (N = 38) to enable exploration for the original study aim. Instead, it was necessary to shift focus to the association between low cognitive function and AT use. However, it is acknowledged that a poor cognition score is not

equivalent to a diagnosis of dementia. Therefore, it is possible that participants had other conditions relating to poor cognition: an acquired brain injury or learning difficulties, for example. Nevertheless, given that most studies on ATs exclude people with poor cognition, this was a useful start.

The second limitation was that ATs used for ADL performance could not be examined. Participants could only select from a set list of devices, most for immobility. They could not describe other ATs they used, or provide their thoughts about device use, unlike in other relevant studies. For example, the Consumer Assessments Study in the USA was similar to ELSA in that it investigated demographic information, health, and disability status of older adults. The aim was to explore ATs used by participants for ADL performance, in order to assist with design improvement and the development of new technologies. Crucially, participants were able to respond to open-ended questions such as: 'What devices do you need that you do not have?', and 'Of all the devices you use, which is the most important to you?' (Mann et al., 1992). These enabled the collection of meaningful data about perceptions and use of ATs for ADLs (Wielandt et al., 2006). Examples include: 'reacher needs to be larger while remaining lightweight'; 'rocker knife is not used because person is not motivated to use it and carer is afraid he will put knife point in mouth'; and 'commode is not recognised by person' (Mann et al., 1992). Such data are needed in order to be able to design appropriate ATs and related services. However, this analysis was limited to the investigation of ATs for immobility only.

A third concern was that it was unknown how participants answered questions about their ADL difficulties. Participants were asked: 'Do you have difficulty doing any of the activities on this card? Exclude any difficulties that you expect to last less than three months'. It is unknown whether respondents answered in relation to their underlying disability or residual disability (Agree, 1999, Verbrugge and Jette, 1994). For example, participant #1 may have indicated that he or she had difficulty dressing, because they were referring to their ability to perform the actions without the assistance they usually received from their carer. Yet, participant #2 might have responded that he or she did not have dressing difficulty since they always had carer assistance. Furthermore, the disablement process model acknowledges that ADLs are context specific (Nagi, 1965, Nagi, 1991), yet participants were not explicitly told to consider their ability to perform the activities in a particular environment, such as their home. Thus, ADL disability is a difficult concept to quantify given the potential discrepancies between participant responses.

The fourth limitation was that some of the health conditions: poor eye health, high blood pressure, other CVD condition, and lung disease or asthma, were not significantly associated with mobility-

related AT use in the final logistic regression model. Yet, statistical insignificance does not necessarily mean there was no practical or clinical significance for that condition on the person's immobility or mobility-related AT use. For example, high blood pressure was not significantly associated with the use of mobility-related ATs according to the logistic regression model. Yet, hypertension is linked to strokes and diabetes (which were both significantly associated with AT use in the model), VaD, and for some people related to obesity or a sedentary lifestyle which may in turn influence use of ATs for immobility (Kaplan, 2002, Skoog et al., 1996, Strandgaard, 1996, Whitmer et al., 2008). Thus, hypertension could have immediate or long-term impact on the use of mobility-related ATs. Overall, it was felt that further in-depth qualitative investigation was needed to explore the intricate relationships between low cognitive function, co-morbidities, ADL disability, and AT use.

6.10: Chapter 6 summary

In this chapter, the method and results of analyses on a large, nationally-representative dataset were presented. The results demonstrated that low cognitive function, the presence of many health conditions, and ADL disability had significant associations with the use of certain technologies for immobility. Therefore, these results contribute to knowledge that older people with low cognitive function are able and current users of mobility-related technologies. However, an investigation of AT use among a specific sample of people with dementia could not be conducted. In addition, ATs for ADLs rather than immobility were not explored as they were not captured in ELSA.

However, ADL difficulties and associated use of ATs are always embedded in context; not only does a person's cognitive and physical functional limitations influence disability and device use, but so do the physical, social, cultural, and attitudinal environments (Agree, 1999, Lawrence and Jette, 1996). Yet, survey methods and statistical analyses control the context and remove an understanding of the influence of surroundings (Yin, 2014). Quantitative data can suggest relationships between variables but not explain why phenomena occur (Bond and Bond, 1990). Use of a walking stick does not mean that it was used effectively or appropriately, or that the person's environment was fully supportive of its use (Agree, 1999). Furthermore, only a cross-sectional analysis was conducted on the data and not longitudinal investigation of how and why circumstances changed over time. It was therefore decided to explore ADL disability and ATs used by people with dementia in a case-based approach. Case studies, each focusing on one person with dementia, would enable a deep analysis of individuals' experience, and capture their carers' perceptions of the role that ATs had. The data collection methods for this case study strategy are presented in Chapter 7 which follows.

Chapter 7: In-depth case studies - method

In this chapter, the methods used to explore the use of ATs for ADLs among people with dementia are presented. The rationale for the research design is described and the creation of multiple case studies is justified. The methods of data collection were in two stages. In Stage One, data from the care records of care home residents with a clinical diagnosis of dementia were extracted. In Stage Two, interviews were conducted with residents' informal and formal carers. The chapter continues with the ethical issues that were considered for the project; these include the assessment of capacity-to-consent to participate in research under the principles of the Mental Capacity Act (2005) (MCA) (UK Parliament, 2005) under which Stage One participants were recruited.

The following two sections in the chapter present: participant selection and recruitment, instruments and materials, data collection procedures, and data analyses for Stages One and Two. A description of the field-site care homes is also given under Stage One in order to set the context within which ADLs were performed and ATs used. Finally, a pilot study that tested the methods of Stage One and Two is discussed. The objective of the methods were to produce comprehensive, contextualised data concerning historic and current use of ATs for ADLs by people with dementia in England, and the perceptions their carers had about its use.

7.1: Study design

The study aim was to investigate informal (family) carers' and formal (paid) carers' perceptions of whether ATs could be used to assist people with dementia to conduct ADLs; and if so, how. This included an exploration of family members' perceptions concerning the contributory role that ATs for ADLs may play in a relocation decision. The research questions and knowledge gaps resulting from the scoping review elicited a need for rich exploratory data, so a multiple case study design was chosen. In this section, case studies are explained and justified as an appropriate research strategy for this study.

A case study is 'an empirical enquiry that investigates a contemporary phenomenon within its real-life context' (Yin, 2003a, p. 13). Possible contemporary phenomenon include: an individual or group of people, organisation, or social or political concepts (Yin, 2003a). To form a case study a unit of analysis, again such as an individual, group of people, or organisation, must also be selected in order to bind the case to specific context (Baxter and Jack, 2008). Context concerns not only the external environment such as the physical space and architecture, societal expectations and attitudes, but

internal characteristics such as demographics, personality, coping strategies, and life history (Scherer et al., 2007). This is in direct contrast to experimental methods, which control the context to measure the effectiveness of an intervention. For example, Mills and Coleman (1994) presented a case study illustrating nostalgic, emotional memories in an 86 year-old male with dementia. The contemporary phenomenon considered was nostalgic memories; the unit of analysis was the person with dementia; and the context was the reminiscence and counselling therapy in which he participated. Bond and Bond (1990) evaluated the National Health Service's three experimental nursing homes and compared them to six hospital wards. The contemporary phenomenon considered was the care outcomes, such as meaningful activity, of patients; the units of analysis were the nine organisational field-sites to enable cross-case comparison; the context was continuing-care of in-patients.

For this study, it was perceived that the ADL impairments an individual with dementia has, and the ATs they use to assist ADL performance, cannot be fully understood without appreciating the context within which that person lives (Scherer et al., 2007). Further, technologies themselves are not neutral objects, and their use can only be understood when situated in contexts (Brittain et al., 2010). A case study strategy was therefore deemed appropriate. The contemporary phenomenon was the use and non-use of ATs for ADLs by people with dementia and their carers. The units of analysis were care home residents with a clinical diagnosis of dementia. This kept the focus of experience on each person with dementia, as not only do the symptoms of dementia affect people in different ways, but their temperament, personality, beliefs, tastes, and many more factors influence their experience (Kitwood, 1997b, Mountain, 2013). The context was the use of these ATs both historically in the community and currently in care homes. The benefit of using a case study strategy for this research was that the phenomenon and context could be studied for the first time in great detail, especially as there were 'who', 'why', 'what', and 'how' questions to be asked (Yin, 2003a, Yin, 2003b). These included: who used ATs, why they used them, what devices they used, and how they were obtained. 'When' questions were also added, for example when ATs were obtained and when they were not used.

Case study strategies are uncommon in gerontechnological research but have been used to explore: women's experiences of using mobility-related devices (Löfqvist et al., 2009); AT use among three people with dementia (Rosenberg and Nygård, 2012); reorientation of a woman with dementia using a computer screen (Baruch et al., 2004); and how two people with mild dementia came to terms with using an AT for memory (Karlsson et al., 2011). These exemplary case studies highlight the

importance of understanding the social context within which people with dementia learn to use, and maintain their use, of new ATs. None of those studies described above investigated ATs for ADLs, or followed AT use over time as the person's dementia progressed. An investigation of technology use over time is needed to understand its contribution to the daily lives of people with dementia. This study was designed to fill these gaps by exploring the short and long-term use of appropriate ATs for ADLs in multiple contexts (community and care home settings and the decision for transitioning between them) by older adults with any type of dementia. The aim was to follow the person with dementia's experience with ATs from life in the community, through the relocation transition, and to their life in the care home. Thus, how the progression of dementia and of ADL disability affected AT use could be captured.

When designing this study, there were two options for following AT use over time: prospectively and retrospectively. A prospective design would follow people with dementia who live at home, observing and recording their ADL disability and AT use over time. The person would likely be in a mild or moderate stage of dementia and thus would participate directly in data collection. However, such a design may be costly and time-intensive; two factors outside of the scope of this PhD study. A retrospective design, looking backwards on the person with dementia's life, was more feasible (van der Steen et al., 2014). Furthermore, an exploration of the role of AT in institutionalisation was required for the fourth research question of this study, and in a prospective design it would be unknown which of the followed people would eventually relocate. People who did not transition were not of interest for this study. A prospective design would mean witnessing in real-time participants' experiences of institutionalisation; from realising relocation may be required, making this decision, organising a move, and the experience of relocating. They may be a particularly stressful and upsetting time for people with dementia and the families; and it was felt that it would be unnecessary for the researcher to witness as it occurred. Thus, a retrospective design was chosen as a valid and sensitive way to explore the role of AT use in institutionalisation events, and of ADL disability and use of devices over time. This design is detailed throughout this chapter. A prospective design is suggested as a future direction from this research in Chapter 10, section 10.9.

Another relevant example of case studies in gerontological research followed four older people to investigate their communication with social services to obtain home modifications (Johansson et al., 2009). The authors recognised that it is impossible to fully understand how potential service users navigate their way through such a system without acknowledging the context of both the person's home environment and their past history to understand how they interpret their experiences. No

case study strategies have been conducted to investigate how people with dementia and their informal carers obtain appropriate ATs for ADLs from social care services. Yet, such data may provide detailed insights into communication between families and services when negotiating the provision of technology.

Case study research can have a single-case or multiple-case design. For example, a research project may focus on the experiences of one 40 year-old woman with early-onset dementia, or may consist of case studies on three such women. A single case study can confirm or challenge a theory (Tellis, 1997), whereas multiple cases are a form of replication and verification. As such it is generally thought that more case studies on a phenomenon produce more certain and compelling results (Burns, 2000, Yin, 2003a). Ten case studies were created in this study; each focused on a care home resident with a diagnosis of dementia. This enabled the historic and current experiences of several residents to be compared and contrasted (Burns, 2000, Herriott and Firestone, 1983, Miles and Huberman, 1994).

The number of case studies selected for a multiple-case design can depend on: the number of rival theories, the intention of providing contrasting results, or maximising what can be learned (Stetler et al., 2007, Tellis, 1997, Yin, 2003a). Furthermore, the case studies may be considered as representative of a phenomenon (similar to others that could have been chosen) or critical (atypical) (Denscombe, 2010). Again, case studies can be used to challenge or confirm a theory or hypothesis (Burns, 2000). The purposive plan in this study was to select and recruit care home residents with dementia who had different demographic characteristics, cultural backgrounds, dementia severity, ADL disability, and use of ATs as indicated from their care record data in Stage One. This plan intended to reach maximum theoretical variation (Ben Mortenson et al., 2012) by creating multiple case studies consisting of people who were as diverse as possible to explore similarities and differences in AT experiences.

A case study is not a method of data collection. It is a holistic research strategy that uses multiple appropriate methods of data collection, the results of which are merged to create the case study (Denscombe, 2010, Stake, 2003, Tellis, 1997, Yin, 2003b). These may involve quantitative or qualitative approaches (Simons, 2009, Yin, 2003a) to gain depth and breadth of evidence (Hutchinson, 1990, Yin, 2003b). For example, Stetler et al. (2009) combined document reviews, questionnaires, observations, and interviews in order to gain a rich description of healthcare organisational structure. The selection of data collection techniques depends on the research

questions being asked (Tellis, 1997). For this study, the data collection methods enabled a meaningful and detailed investigation of AT use and non-use for ADLs in the community and care homes (Burns, 2000, Simons, 2009, Yin, 2003b). Data were collected via care record document review (Stage One) and in-depth interviews (Stage Two).

The data collection was designed in stages for two reasons. First, the care records of all residents with dementia could be mapped to give an overarching view of the ADL disability and AT use of these individuals. Knowledge of all eligible residents would then allow purposive selection of a smaller number of particular residents of interest to form in-depth case studies, as described in the above paragraph. Second, the order of stages enabled the researcher to build relationships with informal and formal carers before they were asked to be interviewed. That is, the Stage One care record mapping process necessitated communication with the resident's family member (informal carer) under MCA (UK Parliament, 2005) guidance for consulting with carers before the researcher met any individuals with dementia, enabling family members to be present while conducting a capacity-to-consent assessment, and later asking them to act as a Personal Consultee (see section 7.2 for details). As a relationship with informal carers was being built in Stage One, it was hoped that these individuals would be more likely to participate when later approached for interview (Stage Two). This strategy was similar for formal carers; staff had seen the researcher around the care home for some time, and a few even facilitated capacity-to-consent assessments and fetched care records for mapping in Stage One. This allowed a relationship to build before they were approached for interview in Stage Two; it was hoped formal carers would be more likely to participate (this was aided by care home managers' agreement that staff could be interviewed during work time).

The combination of the care record mapping and interview methods for Stage One and Stage Two enabled a richer exploration of the phenomenon than data from one method alone. For example, a count of the number of devices in a person's home may provide a cross-sectional understanding of ATs that people in the community possess, but not its use over time, nor users' and families' perceptions of the benefits of technologies. However, this is not to reject the idea that a cross-sectional or large-scale understanding of AT use is beneficial, nor that qualitative methods are a more ethical and valid form of data collection (Brinkmann and Kvale, 2005). Indeed, analyses on a large, nationally-representative dataset presented in Chapter 6 demonstrated the importance of being aware of a person's co-morbidities in addition to their dementia, to fully understand technology use.

For the in-depth case studies, first data from care home residents' care records were extracted (mapped). This was entitled 'Stage One of data collection'. Reviewing data from care records is an unobtrusive and convenient method of collecting health, social, and demographic information (Bowling, 2009, Kellehear, 1993). If available from the care record, data that were extracted included the resident's socio-demographic information; family circumstances; life history; ADL difficulty and subsequent AT use in the community prior to relocation to the care home; informal and formal care arrangements; reasons for relocation of care; the date they entered the field-site care home; and current human and technological care provision in the care home. The data were then mapped into structured vignettes to produce baseline information about each care home resident. More detail on participant recruitment, the mapping instrument, the data collection procedure, and data analysis for Stage One is presented in section 7.5 of this chapter.

In Stage Two of data collection, interviews were conducted with both the resident's keyworker at the care home (their formal carer) and a family member who had contributed to the care of the resident when they lived in the community (informal carer). An interview method was chosen in order to elicit in-depth information on carers' perspectives (Kellehear, 1993). It was not a research objective to interview the care home residents with dementia but to investigate carers' perceptions of the contribution ATs made to their relative's care. The reasons for interviewing carers were fourfold: carers' views are under-represented in AT research; the researcher did not want to subject residents with dementia to a second capacity-to-consent assessment; the severity of residents' dementia meant that collecting meaningful data in interviews may have been difficult; and residents with dementia may have been reluctant to discuss sensitive topics around ADLs, such as their incontinence. This rationale is discussed in more detail below.

First, the scoping review of literature identified that informal and formal carer perceptions were typically excluded in research on ATs for people with dementia, even though they may be the gatekeepers for use of devices at home (Innes, 2009). Second, the residents with dementia whose care records were mapped in Stage One of this study had met the researcher to undertake a capacity-to-consent assessment (see section 7.2 and 7.5 for more details). All but one resident was assessed as lacking capacity to make a decision about whether their care record could be mapped. During assessments, many of the residents were bewildered; others were catatonic. It was felt that requiring residents to undertake another capacity-to-consent assessment to participate in an in-depth interview may have been unnecessarily distressing. Third, a key aim of this study was to get the story of AT use as the person's dementia and disability progressed over time and over location.

Many residents had severe dementia and it was unlikely that any, even among the few who would self-report having dementia or ADL disability, would be able to remember the details necessary for addressing the study research questions. Fourth, ADLs are daily and routine actions but can also be sensitive in nature. The willingness of a person with dementia to disclose their disability may be compromised by a potentially embarrassing topic such as toileting. Researcher observations of these tasks in action were not desired or necessary for the study; it was felt that formal and informal carers' reports on historic and current ADL disability and AT use were sufficient to collect the data. Thus, retrospective interviews with carers were used.

Research asking carers of people with dementia to provide their perceptions of technologies is a useful and informative strategy (Rosenberg et al., 2012). However, there can be some criticism of the interview method; for example, researchers have suggested that retrospective recall of stressful events may be inaccurate among spousal dementia carers (Cavanaugh and Kinney, 1998). Yet, other research has demonstrated that such accounts are reliable (Cotter et al., 2008). As the results of this research were not anticipated to contribute directly to the resident's future care receipt, interviewees had no motivation to under- or over-estimate the person with dementia's abilities when recalling ADL performance. Interview data were then merged with the Stage One vignettes to create full case studies. More information on resident selection, interviewee recruitment, the interview procedure, and data analysis is provided in the description of Stage Two in section 7.6 of this chapter.

In summary, the study design consisted of a multiple-case research strategy. The multiple methods of investigation allowed holistic exploration of carers' perceptions of AT use among people with dementia. The ethical foundations and considerations of this study are presented below.

7.2: Ethical approval and risk management

In the following section, the ethical considerations of the research are discussed. Some of these issues were covered during the ethical approval process for the study, and others are of note. One issue of note is a declaration that the care homes used as fieldwork sites were owned by one care home organisation. These homes were run by a not-for-profit charity which was dedicated to supporting research investigating best quality care. The charity partly-financed this study, alongside the Economic and Social Research Council (ESRC) through a CASE-linked 1+3 PhD studentship. The financial support did not impact on the actions of the researcher, the study design, the findings, or

concluding recommendations. The receipt of funding was disclosed to potential participants during recruitment, and it was stressed that there would be no adverse consequences for residents or informal and formal carers as a result of their opinions concerning the charity.

The study design and ethical conduct of the researcher ensured that the principles of beneficence, non-maleficence, and respect for autonomy were observed, and that participants' privacy and dignity were upheld (Iphofen, 2009, Kellehear, 1993, Woods and Pratt, 2005). This research complied with the ESRC's Framework for Research Ethics (ESRC, 2012) and received ethical approval via the national Social Care Research Ethics Committee (SCREC) in October 2012. Proof of approval is presented in Appendix 4. Approval from SCREC was necessary and appropriate as the study: included participants who potentially lacked capacity during Stage One (so were under the remit of the MCA); involved the social care records of these individuals; and did not involve clinical field-sites such as hospitals or memory clinics. Ethical approval from SCREC enabled the researcher to first assess the capacity-to-consent of care home residents to participate in the study, and afterwards invite them to participate and provide informed consent. These were distinct and ordered steps in the recruitment process and are explained further in section 7.4 concerning the MCA and in section 7.5 when Stage One of data collection is described. As any ethical approval system can only scrutinise the design and preparation of the research, the researcher carefully monitored the research for any ethical dilemmas arising during fieldwork and report write-up (Kellehear, 1993, Sin, 2005).

The researcher was covered by the care home organisation's indemnity insurance while at the field-sites. The researcher also had a Criminal Records Bureau (CRB) check (which has since become the Disclosure and Barring Service) and completed a volunteer form for the care home organisation. The CRB check (see Appendix 4) verified that the researcher was able to work with care home residents and staff (Iphofen, 2009). Positive working relationships were created with the four care home managers. Meetings with each discussed the research design, logistics for fieldwork, and trouble-shooting. At all times the researcher carried photographic identification and paper-based copies of the Research Protocol Summary and Data Collection Flowchart (see Appendix 4) should any non-participant enquire about the research. The researcher had a safety procedure in place when interviews were conducted in private homes. The interview location was disclosed to a colleague who was telephoned prior and post interview to let them know the researcher had arrived and exited. After, the colleague destroyed their copy of the location details. To protect the interviewee's safety, they were able to have someone they knew in the interview room if they wished.

7.3: Data security, anonymity and confidentiality

The care home administrators addressed all postal correspondence to family members. Full descriptions of these paper-based materials are given in the descriptions of Stage One and Stage Two sections in this chapter (7.5 and 7.6 respectively). The researcher held the full names of family carers invited to an interview, but only their telephone number, home address, or email address if these were provided by the potential participant in a returned Study Form. The researcher held only the full name of the keyworkers who were interviewed. Participants' personal details were electronically stored in an encrypted password-protected document. Paper-based information was stored in a locked drawer in the researcher's office at King's College London. A key-card was required to access this shared office. All of the informal carer interviewees were re-contacted to receive a copy of the summary report which was also provided to the care home organisation. Their personal details were then destroyed.

All participants' names were changed to ensure anonymity. The care home names and the charity who owns them have not been disclosed. Interviewees were asked for permission for the use of anonymised quotes to support findings.

Pre-interview, participants were informed verbally and in writing that a Procedure for Breaking Confidentiality was in place (see Appendix 4) were they to disclose anything the interviewer perceived to breach legal or professional codes of conduct. For example, interviewees may have divulged the witnessing of unethical practices while caring for the resident, or the researcher could have observed potential evidence of professional misconduct while at the care homes. Although the Data Protection Act 1998 (DPA) (UK Parliament, 1998) states that only where someone admits to a crime involving a child is the interviewer obligated to report it, the researcher was prepared to take any perceived unethical matters further if necessary. Were this to have occurred, the researcher would have discussed any concerns with the project supervisors. The furthest step would have consisted of contact with the police local to the care home. The Procedure for Breaking Confidentiality was not required during data collection.

Interview recordings and verbatim transcripts were stored in encrypted password-protected electronic files separate from the documents containing participants' personal details. Recordings were deleted when transcription was complete. Only the researcher, who devised the pseudonym codes, was able to identify participants from interview transcripts.

7.4: Informed consent and Mental Capacity Act (2005) considerations

Informed consent is a key consideration in research. It guarantees that participants are made fully aware of the aims, procedures, risks, and the expected impact of the research (Akeroyd, 1988). It ensures participants' understanding of their autonomy and voluntarism (Roberts, 2003), and regulates the relationship between the researcher and participant. Interviewees in Stage Two all provided informed consent before their interview. In Stage One of the research, the care records of care home residents with a clinical diagnosis of dementia were to be mapped. Permission from these individuals was necessary to gain access to their care records and as such they were considered research participants. However, due to cognitive impairment, it may be difficult to determine whether a person with dementia is able to understand the information needed to make a decision such as participating in research. Therefore, people with dementia fall under the remit of the MCA and its stipulations concerning research (UK Parliament, 2005). The MCA applies to anyone who has an impairment of, or a disturbance in the functioning of, their mind or brain which may make them unable to decide, or reduce their capacity to decide, whether or not to agree to take part in research (Dobson and Mental Capacity Act Working Party, 2008, UK Parliament, 2005).

The MCA has been in force since 2007 and applies to anyone involved in the care, treatment, and support of people aged over 16 years in England and Wales who may be unable to make all or some decisions for themselves (UK Parliament, 2005). The primary purpose is to promote and safeguard decision-making of vulnerable people within a legal framework. It empowers people to make decisions alone if possible, and protects people who cannot. The first principle of the Act states that a person must be assumed to have capacity unless it is established they lack it. Guidelines state that an assumption of capacity must not be made based on age, appearance, condition, or behaviour alone. One criticism of this is that merely by having dementia are they subject to an assessment to see if they have capacity or not; something that adults without dementia do not have to undertake. The second principle stresses that a person cannot be determined as unable to make a decision unless all practicable steps to help them have been taken. The practicable steps taken during a capacity-to-consent assessment are described below in sub-section 7.4.1. The third principle of the MCA acknowledges that just because a person makes an unwise decision, that does not mean they lacked the capacity to make it. The fourth principle states that when a decision is made on behalf of someone because they were assessed to lack capacity to make the decision themselves, it must be

made in their best interests. The fifth and final principle states that when a decision is made for another, the option least restrictive to their rights and freedom of action should be used.

For research, the fourth and fifth principles are less rigorously applied in order to facilitate research on this population (Dobson and Mental Capacity Act Working Party, 2008). Indeed, the government and the MCA acknowledge that it is important that research with vulnerable people be carried out, as long as it is conducted according to recognised standards (Mental Capacity Act, 2005).

Vulnerability should not be considered a reason to maintain a history of exclusion in research (Iphofen, 2009). Research with only those individuals who can consent is not a true reflection of life (Warner et al., 2008). However, high standards of research design are needed to minimise the potential for risks and harm (Dewing, 2002). This project complies with MCA guidelines for research projects. As required by the MCA, a capacity-to-consent assessment was conducted with the Stage One potential participants to determine whether they could provide informed consent to have their care record viewed. The content of the assessment is discussed in the following sub-section.

7.4.1: The capacity-to-consent assessment

For research, the assessment for a decision concerns the capacity of a potential participant to consent to their involvement in the project. The MCA is designed to empower researchers and workers in health and social care to assess capacity themselves rather than rely on expert testing (Dobson and Mental Capacity Act Working Party, 2008). However, good training is desirable; the researcher was informally trained by a consultant psychiatrist and received formal training from the Social Care Institute for Excellence.

All assessments of capacity are time and decision-specific. This is especially important to note as people with dementia can have fluctuating capacity to make decisions. The assessment is decision-specific because a person with dementia may be able to make some decisions and not others. For example, they may be able to choose their breakfast but not where they should live. Capacity is also time-specific because a person with dementia may be able to make decisions at some times and not at others. For example, they may be more lucid in the morning but not after lunch because of tiredness or medication. An awareness of these concepts meant that the researcher was able to answer family members' queries about how an assessment could occur when they possessed Enduring Power of Attorney (a previous form of LPA), or more recently LPA, as many believed that having this meant that their relative no longer made *any* decisions alone.

When conducting a capacity-to-consent assessment, an assessor must complete the 'two-step test' to determine the person's ability to agree to participate in the research (Mental Capacity Act, 2005). The first step queries whether there is a disturbance in the mind or brain, not necessarily a diagnosis, which could affect decision-making. If the answer is 'no', the assessment does not need to occur because the person is viewed as possessing the capacity to make the decision in question. If the answer is 'yes', the assessor continues with the second step. This queries whether the disturbance in the mind or brain stops the person being able to make the decision at the time it needs to be made. To answer this second step, the assessor examines four aspects of the person's cognition to determine whether they can: understand information about the decision; retain the information long enough to use it; weigh the benefits and consequences of making a decision; and communicate their decision. If the person cannot demonstrate they can do all four of these tasks the answer to the second step is 'yes; the disturbance in the mind or brain does stop the person from being able to make the decision at the time it needs to be made'.

A particular difficulty for conducting capacity-to-consent assessments is that a lack of response cannot be interpreted as lack of capacity, so the assessor has to be careful about using their own judgement (Dobson and Mental Capacity Act Working Party, 2008). Furthermore, due to the subjective nature of the assessment the reliability of decisions can be queried (Hotopf, 2005). To counterbalance this, the assessment and outcome should be recorded using a tool or form. The forms used in this project are further detailed in the Stage One materials description in sub-section 7.5.3. In addition, after the assessments were completed a sample of the assessment outcomes were evaluated using the online Assessment of Mental Capacity Audit Tool (AMCAT) (Mental Health Foundation, 2010). Anyone who has conducted a capacity assessment under the MCA, with respect to any type of decision, is able to use this software to determine if they conducted it correctly. One of the AMCAT reports is provided in Appendix 4 and shows that the researcher conducted the assessments as ethically, morally, and objectively as possible. Despite some criticisms, the MCA is seen to prevent prejudice and discrimination towards vulnerable populations (Boyle, 2008).

The following two sub-sections discuss the next steps that researchers should take depending on the outcome of the capacity-to-consent assessment. It is stressed here that these steps are specifically related to the guidelines for research projects under the MCA (UK Parliament, 2005, Mental Capacity Act, 2005) and not to other decisions, for example when establishing LPA or institutionalisation. The consent procedure in Stage One and Stage Two are described in sections 7.5 and 7.6 respectively.

7.4.2: Assessment outcome: no capacity-to-consent

If a person was established as lacking capacity to make a decision to participate in the project, the researcher consulted with someone involved in their care and welfare and who was willing to help. Under the MCA guidelines, this individual could not be the person's formal carer but someone such as a family member or friend who had an interest in their welfare (UK Parliament, 2005). Once located, this person then acted as a Personal Consultee (PC). The Personal Consultees (PCs) were asked to advise if the person had been found to possess the capacity-to-consent to participate in the project, they felt in their opinion that their relative would agree to participate. To illustrate, a daughter does not give her *permission* for the researcher to view her mother's care record. Instead, she informs on her perception as to whether or not her mother would have wanted to participate had she been able to decide this for herself. If the PC felt that the person would not have consented to participate, the researcher excluded them from further involvement.

The MCA research guidelines necessitate a Nominated Consultee (NC) to be appointed should a PC not have been identified, or an identified main family carer refused to act as a PC (UK Parliament, 2005). The NC could be a paid carer, GP, or solicitor, as long as they were not involved in the project. In this instance, the researcher would have worked with the care home manager to identify a potential NC. This did not occur in this study.

7.4.3: Informed consent procedure for all participants with capacity-to-consent

The potential participants assessed as possessing the capacity-to-consent then came under the usual informed consent procedures for adults not considered vulnerable who are assumed able to provide informed consent. However, even such research participants may not fully understand what they are consenting to (Iphofen, 2009, Sin, 2005). Consequently, the researcher was careful to observe whether or not any potential or actual participant in Stage One or Stage Two understood the information given to them (Woods and Pratt, 2005).

Information given to participants with capacity (that is any assessed in Stage One as having capacity and all interviewees in Stage Two) included what their participation involved; the potential risks; confidentiality; anonymity; and their right to refuse participation or withdraw data (Sin, 2005). Of particular importance was that participants fully understood the benefits and potential costs of their participation. There were no negative consequences for individuals as a result of their non-participation (Lee, 1993). It was stressed that family members and residents' relationship with the care home would not be compromised (Tinker, 2007). Congruent to guidance on conducting ethical

research, information acknowledged that the research was not expected to cause undue harm (Camprion-Smith, 2007), although one 'harm' to interview participants was the time spent being interviewed (Iphofen, 2009). The researcher did not have funds to reimburse interviewees for travel expenses or financially compensate them for their time. Participants were informed that although there may be no immediate benefits for them, it was hoped that they would find the experience enjoyable and be rewarded by the knowledge that their participation in the study would contribute to the greater understanding of the role ATs play in dementia care. A second possible harm was that the interview topics were sensitive as they required participants to recall emotional and private experiences. For both interviewees and interviewer, an issue was the ability to remain composed when discussing private or sensitive matters (Lee, 1993). A Procedure for Those who Become Distressed was approved by SCREC; this is included in Appendix 4. This procedure was to be put into action if interviewees became upset, and they were to be informed they did not have to answer every question, could pause or stop the recording at any time, and that they could withdraw their data at any time up until their interview was completely transcribed. This procedure was designed to maintain participants' sense of control (Camprion-Smith, 2007).

Paper-based consent forms recorded participants' acknowledgement that they gave informed consent in writing. The researcher also signed the consent forms to acknowledge that she had provided full information on the research and data collection procedures, and answered any questions the participant had. More information on the consent form for each type of participant is provided in Stage One and Stage Two descriptions (7.5 and 7.6 respectively).

This concludes the ethical considerations for the case study aspect of this research project. Greater detail on each stage of data collection will be presented in turn below. The sub-sections are structured in the following order: participant selection and recruitment, the instruments and materials used, the data collection procedure, and the analyses conducted on the data.

7.5: Stage One of data collection

In Stage One, a vignette was created for each participating care home resident with dementia. Data were mapped from each resident's personal social care record held at their care home. Primarily, the data were used to select residents for future in-depth case studies. The data were also used to collect baseline information on all participating care home residents with dementia.

7.5.1: Participants

This study focused only on care home residents with a clinical diagnosis of dementia. People with MCI, the precursory condition to dementia, were excluded because some experience a reversal in their cognitive decline (Brooks and Loewenstein, 2010). All care home residents with a clinical diagnosis of dementia were eligible to become the focus of a case study. Descriptions of the number of potential and actual participants at the various stages of assessing and acquiring consent are below. The Stage One Procedure to identify and recruit participants is provided in sub-section 7.5.4.

Initially, 56 residents were eligible across the four care homes to have their care records mapped in Stage One. It is not known how many total residents lived at the four care homes at the time. After consultation meetings with informal carers, 39 out of the 56 potential residents participated in a capacity-to-consent assessment. The 17 residents who did not participate were: 14 residents whose relatives had advised the researcher against the assessment; one resident who moved to palliative care; one resident who became hospitalised; and a final resident who was out of the home for a holiday during the assessment period. The 39 assessed residents consisted of six males and 33 females across three care homes. The fourth care home initially considered as a field-site did not typically provide dementia care, and had only one potential participant. That person's family advised against the assessment for capacity-to-consent. Of the 39 residents, one had capacity-to-consent. This person consented to have their care record mapped.

Following assessments, there were 38 residents who lacked capacity-to-consent to participate in the study. The families of 37 residents were contacted to be PCs, as one resident died shortly after their assessment. The PCs of 20 residents recommended that their relative would not wish to be involved had they the capacity-to-consent to participate in the project. Therefore, it was anticipated that the care mapping exercise would be conducted on 18 residents: that is, on the one resident described above who had provided informed consent in addition to the 17 residents following communication with their PCs. However, one of these residents died and another moved to a different care home before their records could be mapped. Thus, the care records of both of these residents were no longer available. In total therefore, 16 care records were mapped for one male and 15 females across three care homes. Illustrative flowcharts of the Stage One participants and drop-out numbers, both in total and within each of the four care homes, are provided in Appendix 4.

7.5.2: Description of care homes

Throughout both stages of data collection, field notes were taken to describe each of the care homes. This was to illustrate the physical environment within which residents lived and ADLs were performed, given that an ADL is a socially-defined activity (Nagi, 1965, Nagi, 1991). The descriptions were formed using facts about the care homes from the charity, the researcher's observatory field notes, and conversations with the care home staff during data collection.

The care homes were owned and run by a not-for-profit charity and provided residential care, nursing care, and respite services. As such, the homes are referred to throughout this thesis using the generic term 'care home', rather than 'residential care home' or 'residential care and nursing home'. The care homes, coded 'Care home #1', 'Care home #2' and 'Care home #3', were equipped to care for residents at any stage of dementia. A fourth potential field-site, 'Care home #4', provided residential care only. Future references to 'the care homes' refer to Care home #1, #2 and #3 only, and not the fourth care home which did not become a field-site.

Each home had managerial, administration, cleaning, estates, and kitchen staff, in addition to nurses who administered medication and medical aid, and formal carers who provided social care (ADL assistance, for example). There were also night carers and night nurses responsible for night-time social care, nursing, and monitoring the sleep patterns of residents. Throughout Chapters 8 and 9 any reference to 'formal carers' or 'staff' refer only to the employees who provided social care to residents, unless indicated otherwise. Each care home had a keyworker system; keyworkers were formal carers of senior level status who were each assigned a number of residents for whom they were the first 'point of call' in communication about that person. Keyworkers were responsible for keeping those residents' care records up-to-date and were perceived to know more about 'their' residents than other staff members. No nursing staff or night carers were keyworkers. The keyworkers were those employees targeted for key informant interviews in Stage Two.

With regards to obtaining new ATs, the staff nurses, GP, physiotherapist, or a specialist visiting continence nurse were typically responsible for assessing the need for, or trial of, a new AT for a resident. The formal carers also continuously monitored residents for changes in their behaviour and abilities, and were able to suggest use of a new AT. In many instances, nurses did not need to be involved for a new AT to be implemented. For example, a formal carer observed that a resident with dementia was having difficulty pushing food onto their fork, so asked the resident if they would like

to try a plate guard. There was no need for the formal carer to consult with nursing staff about the introduction of such a technology. However, if a resident was incontinent only a visiting specialist continence nurse could evaluate which continence pads the person should use. Formal carers were required to record in the resident's care record if they introduced a device to them.

The care homes provided frequent social activities for residents, such as games, singing, arts, and crafts. The gardens of the care home were well-designed and one had a sensory rockery-garden and pet rabbits for residents to care for. Estates staff conducted regular improvement work; for example the pathways in the gardens of Care home #1 had recently been tarmacked for more accessible wheelchair use. More details on the facilities within each care home are presented below.

7.5.2.1: Care home #1

In Care home #1, the six residents with a diagnosis of dementia resided in a new purpose-built wing on the ground floor. The main reason for this was that other residents without cognitive impairment had become distressed by the mannerisms of some of the residents with dementia, such as shouting. However, the wing was not intended to permanently separate or lock residents with dementia away from those without cognitive impairment, so access was open. Residents could enter the other areas of the home if they wished, and did for some activities such as to use the hairdressing room or mechanical bath. All doors leading to outside had electronic codes to prevent residents with dementia from leaving unannounced.

The corridor walls of the wing were cream-coloured with a red hand-rail. The carpet was red. The corridor had attractive flower and landscape artwork. The fire-door at the end of the corridor was painted to look like a bookshelf to discourage residents from using it inappropriately. Each resident's bedroom door looked like a house door, with a real knocker but non-working letterbox. The doors had the resident's name and some also had a picture, such as a beach. Room signs were on all the doors, and labels were on most room furniture. Bedrooms included armchairs to convey the atmosphere of a bedsit or flat. The bedrooms had a change in carpet from the corridor. All bedrooms had an en-suite facility, although the corridor also had a main bathroom.

The wing housing residents with dementia had a bathroom that was light blue with pictures of fish on the walls. It was a wet-room, so was tiled on the floor and walls to enable residents to walk straight into the shower zone. There was a white curtain to be pulled around the shower space. The shower area had a sign detailing the steps of how to wash; this had been requested by a resident

who could wash herself but had forgotten the steps. There were dark blue handles in the shower area and around the toilet. The toilet seat was the same dark blue to contrast with the white porcelain, although it was not raised. A grey and white shower seat was fixed to the wall. There was a call button. There were yellow wet-floor signs. There was no bath. There was a shelf upon which were a box of rubber gloves and a yellow bin for disposing hygiene waste such as continence pads (Health and Safety Executive, 2014). There was a small sink in the corner at hand height; this was difficult for the researcher to use for hand-washing as it was so petite. The sink had cross-head taps and a liquid-soap dispenser on the wall. There was also a hand towel dispenser and bin.

The dementia wing had a kitchenette and adjoining dining room set up like a café. The kitchenette had yellow walls. There were home-made signs on the cupboards and drawers: 'cooking utensils', 'cutlery', 'mixing bowls', 'saucepans', 'food', 'cups/mugs', 'plates', and 'bowls'. These were to help residents make cups of tea and wash pots if they wished. There were clear boxes containing cereal, each labelled with the name of the product inside. There was a small table to increase surface space. The kitchenette had a white fridge, an oven with stove-top, and a sink. Tea, coffee, and sugar jars were labelled and placed next to a kettle. There was a fire blanket and fire extinguisher. The kitchenette opened out to the dining room; there was also a door from the dining room to the corridor. This door was white, with a way-finding orientation sign of orange lined in black with a larger-than-life photograph of real food and cutlery. The dining room area had two round tables, each with space for four people to sit. When set for meals, placements included a small glass tumbler and cloth napkin. The dining room also acted as an activity room for crafts, games, and art. There were paintings on the wall from previous activities. There was a photo-poster that residents had completed, entitled 'In the Garden'. The lightshades were tartan. A resident's personal family photo was on the windowsill alongside a glass vase with fresh flowers. A radio on the windowsill was of 1950s design, but carers could plug a digital music player into it to play old songs and radio programmes. The back garden and the care home's rabbits could be seen through the window.

There was a lounge at the end of the corridor. The door had a green 'Lounge' sign with a picture of a red armchair. Inside were two 1950s-style armchairs and a sofa. There was an old lamp, wooden tables, and a gas fire that was designed to look like a wood fire. The TV was of modern style. There were paintings of flowers and a mountain. There were blankets, dolls, knick-knacks, and more old photos. There was a French door to the garden, but curtains could be pulled over this if necessary. There was also a reminiscence room. The way-finding sign on the door was yellow with a photo of a 1950s-era radio and a rotary-dial telephone. The reminiscence room contained a Reminiscence Pod

(RemPod) (RemPods, 2015). A RemPod is a set of items of 1950s design that can be bought as a package. It included a lightweight, portable aluminium frame with art deco style wallpaper on one side and a picture of a dance-hall orchestra on the other. There was a 1950s-style television and radio, and 1950s-style furniture, digital video discs of old black-and-white programmes, an old sink with washboard, old photographs in frames, a brass ember pan, a xylophone, and a box with different textiles to touch: fur, denim, velvet, and more.

7.5.2.2: Care home #2

In Care home #2, residents with dementia were interspersed throughout the multiple wings. The home had two floors and lifts to enable residents with poor mobility to live upstairs. Residents were entitled to go anywhere in the care home with the exception of the catering kitchen, staff break-room, and the managerial office. One resident with dementia particularly enjoyed sitting in the nurse's office, and was frequently observed by the researcher in there 'filing papers'.

The architecture and environment was not designed specifically for people with dementia, but the care home manager advised that there was an environmental modification plan currently being implemented. This would adapt the home to be more dementia-friendly. The plan included: a re-paint of bedroom doors to be more noticeable, to make hand-rails brightly-coloured, and to paint doors leading to off-limit areas the same as the surrounding corridor wall. There were multiple large spaces on both floors that acted as sitting rooms, dining rooms, and activity rooms. The largest of these was on the ground floor and was adjacent to the kitchen; this room was set up for dining prior to mealtimes. It seemed that residents typically sat in the same, or possibly their preferred, room every day. Some of the rooms had armchairs and dining chairs but many residents sat in their own wheelchair or water-chair that had been ergonomically fitted. Some residents conversed and others did not hold conversations. On one visit, the researcher observed an altercation in the reception area involving three female residents who self-propelled their manual wheelchairs using their feet. The ladies would not allow each other to pass in the space available and instead purposively rammed into one another. No carers were present to intervene at that time, but eventually assisted when the shouting caught their attention. They did not talk to the residents about their behaviour but wheeled them into different sitting rooms. Witnessing of this altercation confirmed that some residents were able to use their mobility-related ATs alone.

Many residents' bedrooms had en-suite facilities but there were bathrooms on each corridor. These all had a way-finding AT sign indicating that a toilet could be found within. Some toilets had blue

seats and all had hand-rails, except for a small visitors' bathroom near the reception. The home had two mechanical baths, but no shower facilities. A hairdresser visited every Wednesday to run a salon in a dedicated room. The same GP had visited Care home #2 every Tuesday for over 20 years. The reception area had a digital photo stream of deceased residents. There were many social activities for residents, including poetry nights run by an ex-informal carer of a deceased resident.

7.5.2.3: Care home #3

Care home #3 was entirely on the ground floor. It had four wings, one of which was empty for refurbishment. This refurbished wing was designed specifically for people with dementia, and was to have a living room and kitchenette styled as a 1950s-era home. The wing was to have a separate activity room containing relevant articles for weekly faith services. The bedroom doors were designed to look like front doors, as in Care home #1. The occupied wings had large living room spaces, with tables and chairs for dining, armchairs and televisions, and kitchenettes for staff to prepare drinks. Each had patio doors that opened onto garden spaces. There was also a very large room in the through-way to two of the wings, for hosting social activities. This contained the home's aquarium, comfy seats, and a bar area where tea could be prepared. Residents were not discouraged from walking throughout the care home, apart from restrictions on the staff-only offices and the new wing under refurbishment.

The home had a dedicated hairdressing room for all residents. This was next to the largest bathroom, which contained both the mechanical bath and wet-room shower facilities. All bathrooms throughout the home had way-finding AT signs. Some bedrooms also had en-suite facilities. Most toilets did not have coloured or raised seats, but all had white hand-rails.

7.5.3: Care mapping instrument and other materials

In this sub-section, the materials needed to complete Stage One are outlined. This list includes the mapping instrument, letters and various forms used to communicate with family members and care home residents when gaining consent and collecting data.

The researcher did not know precisely what data were held in each care record before mapping began. A care mapping framework (see Appendix 4) was created based on published literature and discussions with research supervisors. Previous studies with care home residents have used medical charts and administrative records to collect data on age, gender, ethnicity, marital status, date of arrival and length of stay, functional status, depression, co-morbidities, medication, and the level of

support needed for ADLs at home (Challis et al., 2001, Edelman et al., 2004, Fossey et al., 2006, Hardy et al., 1999). Crucially and most importantly for this study, data concerning ATs used when the resident lived at home, if included in the record, and current AT use in the care home were desired. The data collected in the record mapping exercise were essential for understanding the historical and current context within which the people with dementia and their carers existed. However, residents' ethnicity and full birth date were not mapped as this may have put their identity at risk. This is not to say that ethnicity data may not have been beneficial to the study. Racial and cultural differences exist in both the aetiology and prevalence of dementia (Miles et al., 2001, Weintraub et al., 2000) and informal carers' perceptions of stress, coping, and awareness of support services (Janevic and Connell, 2001, Connell and Gibson, 1997). Ethnic differences in accessing formal services may also influence the understanding of AT use in community settings. However, for this study reducing the risk of identification and ensuring anonymity were felt to be more important than the need to investigate ethnicity.

The care mapping framework divided the data to be collected into three sections. The first section collected demographic and health data: gender; birth year; marital status; the date the diagnosis of dementia was made; current estimate of symptom severity; and dementia medication use. The second section mapped care arrangements before the person was institutionalised: where they lived and with whom; what informal care was provided and by whom; formal care services coming to their home; respite arrangements; day centre or other relevant group attendance; hospital admissions; difficulties with ADLs; and ATs used for these. The third section mapped care arrangements after relocation to the care home: the date of relocation; why this occurred; their keyworker, family, and friends listed as contacts or visitors; if the person was considered able to leave the care home alone or with family members; need for ADL assistance; any other specialist care; and use of ATs for ADLs. There was space for additional information if required.

The main family contact for each eligible resident was sent a Pre Data Collection Family Letter and Pre Data Collection Form (see Appendix 4) to notify them that their relative had been identified as a potential research participant. The Pre Data Collection Family Letter explained the purpose of the research, the capacity-to-consent assessment, and an invitation to a consultation meeting with the researcher for more information. The form enabled responders to notify their attendance at the meeting and advise the researcher if they perceived their relative would not wish to be involved. A stamped envelope addressed to the researcher was included to enable families to return the Pre Data Collection Form at no cost to themselves.

Several materials were created for the capacity-to-consent assessments with residents. A simple Resident Information Sheet (Appendix 4) was used to explain the project to potential participants with dementia. Presenting the information in different ways facilitates understanding as much as possible, a key principle of the MCA (UK Parliament, 2005). The Resident Information Sheet used brightly-coloured illustrations, large font, and simple words. This material was created because extra consideration is required to ensure the understanding of people with dementia (Sin, 2005). Verbal and behavioural consent from potential participants with dementia is acceptable and valid (Bamford and Bruce, 2000), although creative methods such as video recording and Yes and No cards can also be useful (Wiles et al., 2007). Indeed, the Resident Information Sheet contained Yes and No illustrations to help potential participants understand they did not have to participate.

The researcher completed both an Assessment of Capacity Form and Decision-Making Form (Appendix 4) to record the outcome of the capacity-to-consent assessment. These forms were important for providing a clear evidence trail clearly stating how and why the decision was made and to ensure that all steps had been made to assist the person to make the decision themselves (Dobson and Mental Capacity Act Working Party, 2008). The forms contained the two-step test and the four determinants of capacity as described earlier in sub-section 7.4.1. They were based on forms already used by the care home organisation during capacity-to-consent assessments as part of their social care work for residents and their own research activity. Published commercial tools to record a capacity assessment do exist, for example, the MacArthur Competence Assessment Tool – Treatment (Grisso et al., 1997) which is USA-based and obtainable for a fee, and the BPS Audit Tool for Mental Capacity Assessment (The British Psychological Society, 2010) which can be found online for free. These tools can be used to record any type of decision; it is only the steps after the assessment that become research and non-research specific. However, these tools are time-consuming and overcomplicate the matter by requiring the researcher to assign scores to the sections. If the MCA guidelines are followed, a commercial tool is unnecessary. It is noted that the MMSE does not predict presence of capacity, and so is unsuitable for such a purpose (Warner et al., 2008, Woods and Pratt, 2005).

Residents who had capacity-to-consent signed the Resident Consent Form (see Appendix 4). This ensured that the participant acknowledged in writing their receipt and understanding of the research brief. A Courtesy Letter (Appendix 4) was then posted to their informal carer to let them know that their relative had consented to participate.

If a resident did not possess capacity-to-consent, Personal Consultee Letters and Personal Consultee Forms were posted to their main family contact (Appendix 4). A stamped, self-addressed envelope was included to encourage return of the Personal Consultee Form.

7.5.4: Procedure

In this section the procedure for Stage One is outlined. There were many steps to recruiting potential participants ethically and in compliance with the MCA. This section includes: the process of consultation with family members; capacity-to-consent assessments and procedures depending on the outcome; and finally how data were mapped from the care records. The same procedure was followed within each field-site care home.

After an initial meeting with the care home's manager to discuss the project, the researcher met with the care home's administrator to provide Pre Data Collection Letters and Pre Data Collection Forms in stamped envelopes. At this stage the researcher did not know who, and how many, eligible residents there were. The care home administrator identified the main family carer for each resident, addressed, and posted the packs directly to them. The Pre Data Collection Letter outlined: the study aim; the methods of data collection and what was to be mapped from the care records; the need for a capacity-to-consent assessment with each resident; the protocol if a resident became upset during assessment; an assurance of confidentiality; an option to opt-out (that is, advise that the assessment should not occur); an invitation to an information meeting at the care home about the project (to occur before any assessments were made); and a notification that the family member could be present at the assessment if they wished (and options to change this to a more convenient time). Recipients were to complete and return the Pre Data Collection Form in the stamped addressed envelope provided. This enabled family members to respond and indicate whether they intended to attend the information meeting, the assessment or whether they advised against the assessment. The Pre Data Collection Letter stated that non-responders were considered to have been consulted on their relative's participation in the research and thus the capacity-to-consent assessment would go ahead.

Meetings with the relatives were arranged at the four care homes. This consultation process involved: further description of the research and the principles behind it; information about the NDS (Department of Health, 2009); the MCA and capacity-to-consent assessments (UK Parliament, 2005); an explanation of the DPA and its principles relating to the research (UK Parliament, 1998); and

relevant personal and professional history of the researcher including her voluntary experience with people with dementia. Documentation to support these topics, such as the MCA Code Of Practice (Mental Capacity Act, 2005) and the Dobson and Mental Capacity Act Working Party (2008) report on conducting MCA-compliant research, were provided. The researcher was open about the care home organisation's involvement in the project as both part-funder and gatekeeper. Assurances of anonymity, confidentiality, and unlikelihood of negative consequences were made.

In Care home #1, the consultation meeting occurred on the same date as the scheduled relatives' meeting at the home during a weekday evening. However, no relative who had been contacted for this study attended the relatives' meeting. This is not to imply that family members had not had some contact; some had already contacted the researcher privately about the study. An evening weekday meeting was arranged at Care home #2 to which three family members attended. One attendee had already expressed a wish for the assessment not to go ahead, but came for information regardless. The other two attendees agreed that an assessment could go ahead after the meeting. At Care home #3, the meeting occurred on a Sunday afternoon and was attended by six family members. Some of these were multiple attendees for the same resident, typically where siblings had either Enduring Power Of Attorney or LPA and wished to be equally informed. There was one eligible potential participant in Care home #4. The researcher met with the resident's spouse to discuss the study and also spoke via telephone to the resident's adult child. Both advised that the assessment could occur. However, the day before the capacity-to-consent assessment was scheduled, the family changed their decision. Care home #4 was no longer a field-site. To summarise, many family members of the care home residents did not attend the relative's information meeting, but this was not a pre-requisite to the resident's involvement. The Pre Data Collection Letter, Pre Data Collection Form and meetings with relatives fulfilled MCA requirements that others should be consulted about the project before involving any vulnerable adult (Mental Capacity Act, 2005). Legally, the researcher did not have to take families' advice if they preferred for a capacity-to-consent assessment not to occur, but did so as this was perceived ethically and morally appropriate and may otherwise have hindered her relationship with the care homes and future PCs.

A list of residents with a diagnosis of dementia was provided to the researcher by each care home manager after the consultation process with family members had occurred. The names of residents whose families did not want them to be involved were not included on these lists. The capacity-to-consent assessment utilised the Resident Information Sheet, Capacity Form and Supported Decision-Making Form to determine and record capacity of potential participants. The care home managers

or staff advised on an appropriate time for assessments, for example not during mealtimes when residents may have been distracted or after medication when they may have been drowsy. Family members or formal carers were present for some assessments to assist the researcher with interpreting the resident with dementia's communication.

The assessment was a dialogue. The assessor (the researcher) discussed the project with the resident, the study aim, and what the person's participation would involve. The assessor outlined the consequences of deciding; if they agreed to participate their care record was to be viewed, and if they decided not to participate there were no adverse consequences. To be deemed as possessing capacity-to-consent, the person needed to communicate in some way that they had understood, retained, and weighed the information given to them about the research.

When a resident was found to possess capacity-to-consent and they wished to participate in the research, they signed two copies of the Resident Consent Form. They retained one copy. A Courtesy Letter was sent to their main family carer to notify them of the outcome. Should a resident have been found to possess capacity-to-consent but did not wish to participate, their care record would not have been viewed. The procedure to consult with PCs regarding relatives without the capacity-to-consent was described earlier in sub-section 7.4.2. Non-responding PCs received a telephone call from the care home administrator after a few weeks to prompt them about the Personal Consultee Form. Some then returned the form, others expressed verbally that they perceived their relative would not take part. Nominated Consultees were not required.

The researcher was provided with a private area in each care home in which to view the care records. A paper-based copy of the Mapping Framework was used to collect data, but it soon became apparent that there was more information in each record than could be recorded using the form. Many pages of notes were produced at the end of each mapping exercise. It took approximately three hours to work through one care record. It therefore necessitated multiple visits to each care home to complete Stage One of data collection.

7.5.5: Analysis

The data collected during the mapping exercise were transformed into prose to create a vignette linked to each participating resident. Vignettes are manageable summaries of the data to enable ease of understanding, and have been used as a qualitative method to summarise and reveal interesting points about research populations (Miller et al., 1997). The vignettes were then

compared to identify the different care circumstances experienced by the residents (McDonnell et al., 2000). Although the vignettes did not contain enough data to address the research questions of this study fully, they were able to illustrate the different ADL difficulties of the residents with dementia and the ATs used by and with them. They were also used to select variety of the Stage One participants for further exploration using case study strategy in Stage Two.

7.6: Stage Two of data collection

In Stage Two, interviews with informal and formal carers enabled in-depth exploration of the ATs used by and with the care home resident. The interviews were focused on the subjective experiences of the key informants to investigate the residents' difficulty in conducting ADLs, AT use in both settings, and the circumstances leading up to relocation of care.

7.6.1: Participants

From the 16 residents who participated in the care mapping exercise, all were selected for further investigation. It was originally intended that the data in the vignettes would inform the selection of particular cases of interest for further investigation in Stage Two. In the original design, it was hypothesised that all 56 eligible care records would be mapped and approximately 15 of these would be selected for Stage Two. It was intended that purposive selection, a method more appropriate for case study strategies than random sampling (Stake, 2000), would be used to choose residents to represent a variety of circumstances in relation to family composition, community care, type of dementia, and varying difficulties with ADLs (Ben Mortenson et al., 2012, Denscombe, 2010, McDonnell et al., 2000, Stetler et al., 2007, Tellis, 1997, Yin, 2003b). However, due to the high drop-out and low participation rate in Stage One, the researcher and supervisory team decided that family members of all 16 residents were to be invited for an interview in Stage Two. One resident died at that time so the families and keyworkers of 15 residents were invited to participate.

As the residents with dementia were not interviewed, interviewees needed to be people with a significant role in their lives, known as 'key informants'. 'Key informants are often critical to the success of a case study' (Yin, 2003b, p.90) as they can provide both retrospective and current perceptions and experiences of AT for ADLs (Simons, 2009). By interviewing keyworkers and informal carers, each case study could draw on multiple experiences. This was designed to reduce bias that may have occurred were the case study to rely heavily on one key informant. The possible disadvantages of poor interviewee recall and articulation still applied (Yin, 2003b). Although there

were no strict exclusion criteria for key informant eligibility, the researcher did not have funds to pay for a translator. Therefore, potential interviewees who could not speak, read, or write English were ineligible for interview. However, this did not occur during Stage Two of data collection. The researcher would have striven to include potential participants with special communication needs. For example, interviewees who were deaf could have been accompanied by a sign-language interpreter or submitted written answers to the interview questions. Again, this did not occur.

The study design enabled interviewees to suggest other keyworkers, family, or friends who had knowledge to contribute to the case study. Therefore, it was possible that some participants could be identified by snowball sampling. When all potential informal key informants of a resident declined to be interviewed, the keyworker was not invited for interview and the resident did not become a full case study.

Due to lack of interest from families of five residents with dementia who had been in Stage One, in total there were 10 case studies created following Stage Two of data collection. Interviews were conducted with 10 keyworkers and 11 family members (two siblings were interviewed together for one case study). Multiple flowcharts provided in Appendix 4 present the total numbers of interviewees in Stage Two and the number of participants sourced from each of the three care homes. There were seven female adult children and two male adult children interviewed. One female spouse also participated; the lack of spousal participants reflected the typically widowed state of the residents. In one case study, the immediate family member was the nephew of a resident. He recommended that his wife, the resident's niece-in-law, be interviewed as she had more knowledge of his aunt's care. All 10 keyworker interviewees were female. Male carers were employed at the care homes but none were keyworkers assigned to the residents under investigation. Although it did not happen often, in some circumstances a resident's keyworker did not know them well enough to contribute. For example, they had only just become the person's keyworker so were not the most knowledgeable source of information. In such cases, a previous keyworker or experienced staff member with appropriately detailed knowledge participated instead. Age and other demographic data were not collected from interviewees.

7.6.2: Interview topics and other materials

In this sub-section, the topic guides for the two types of interviewees and the recruitment and briefing materials used to obtain participants in Stage Two are listed.

Separate topic guides were created for family members and friends, and keyworkers (Appendix 4). The interview topics covered the five factors suggested by Brown et al. (2004) when conducting holistic research: person factors, context factors, activity, experiences, and well-being. Interview topics for informal carers concerned: their experiences of the difficulties in assisting with the person's ADL needs and how these difficulties may have been related to the need for entry into a care home; whether ATs were used for ADLs; how they obtained ATs; if they perceived AT use to have delayed institutionalisation; their perceived barriers to ATs; and relationships with community care services. Interview questions for keyworkers concerned: their dementia specific training; how ATs were used with the resident while residing in the care home; their perceptions of the value of this; and whether they thought ATs could improve care home and family relations.

Family members and keyworkers received Interview Invitation Packs consisting of an Interview Invitation Letter, Information Sheet, and Study Form to be returned in an enclosed stamped envelope. These can be viewed in Appendix 4.

Prior to the interview, both participants and the researcher signed two copies of the Interviewee Consent Form (Appendix 4). Participants retained one copy. This ensured that both possessed a written record that the interviewee had: been briefed about the research, had the opportunity to ask questions, understood the withdrawal procedure, consented to be recorded, and were happy to receive information about the study results.

Interviews were recorded on an Olympus WS-321 M Digital Voice Recorder. Recordings were uploaded onto the researcher's university personal computer. The device worked with Windows Media Player software which was already loaded onto the computer as standard.

7.6.3: Procedure

This sub-section outlines the protocol for recruiting and conducting interviews for Stage Two. This includes the procedure for ensuring that ethical guidelines were followed, the type of interviews, and transcription.

Interview Invitation Packs were posted to family members. The care home administrator addressed the envelopes. The Family and Friends Study Form within the packs enabled potential interviewees to express any interest in participating via post. They could alternatively use the contact details to email or telephone the researcher. If contact had not been made in some way after three weeks, the

care home administrators conducted follow-up telephone calls on behalf of the researcher. Two potential participants received follow-up emails from the researcher because they had previously been in contact via email during Stage One. The keyworker for each selected resident was informally asked either face-to-face or via telephone at the care home to participate in an interview. They were then given or posted a keyworker Interview Invitation Pack.

Convenient interview dates and locations were then arranged. There were 20 interviews in total with 11 informal carers and 10 keyworkers for 10 care home residents with dementia. Eighteen interviews took place in a designated quiet room at the care homes and two occurred at the homes of informal carers. Before the interview began, participants received a second copy of their Information Sheet to remind them of the study, and the procedures of the interview were re-explained to them. They were given time to ask questions or request further information if needed. Participants signed two copies of the Consent Form and retained one.

The interviews were semi-structured in nature, as structured interviews lack flexibility and spontaneity (Kvale and Brinkmann, 2009). Therefore, the interviewer was able to explore unanticipated topics when they arose, to probe the participant further and thereby obtain rich data (Merton et al., 1990, Wengraf, 2001). This interview strategy was able to produce insightful data targeted on the specific topic, while also reducing the likelihood of researcher bias arising from a strict question schedule (Yin, 2003b). That is, to obtain data drawn from the participants' experiences and not only to collect rigid answers to questions created entirely by the researcher. Afterwards, participants were debriefed (for example, it was reiterated that they could withdraw information up until the time of transcription), and thanked for their time.

The interviews were digitally-recorded. Verbatim transcripts for each interview were created from the recordings. The transcription style used no punctuation in the participants' dialogue to avoid changing the meaning or intent of the comments made by interviewees. Question marks were added to the interviewer's questions as she was aware of the intent of her own comments. Quotation marks were, however, added to participants' dialogue when they quoted something that they or another person had said. Comments such as 'erm' and 'mmm', notes such as '[laughs]' and '[points out of the window]' as well as the interactions between interviewees (in the case of the sibling joint interview) were included. This ensured that an accurate representation of the interview was created before data analysis. Potentially identifiable names or places were anonymised, for example '[hospital]' and '[town]'.

7.6.4: Analysis

There were two interview transcripts for each case study in Stage Two; one each from a keyworker and a family member. The data from these transcripts were merged with the vignettes from Stage One to create a detailed, chronological case study for each of the 10 residents. That is, case studies were ordered in time sequence and by ADL to show how individuals' disability changed from living in the community to residing in their care home.

Then, the care record data and interview transcripts were subject to a cross-case comparison. A thematic analysis was used to identify patterns of experiences within the data (Braun and Clarke, 2006). A cross-case comparison using thematic analysis is appropriate for case study analysis (Flick, 2014, Stetler et al., 2009). The qualitative data analysis software NVivo, version 9, was used to facilitate this. In the first wave of analysis, both semantic codes (from the words actually used) and latent codes (meanings behind the words) were made (Flick, 2014). The initial coding structure was generated from the analysis of the care record data and multiple interview transcripts for Case A (the first resident with dementia whose data were turned into a case study), and then modified as care record data and interview transcripts for the other residents were analysed (Flick, 2014). These codes were put into 'initial themes'. These initial themes were split or merged in a second wave of analysis, using a deductive approach to have more close accordance to the study research questions (Braun and Clarke, 2006). These resulted in five 'potential themes'. These potential themes, and in particular their sub-themes, were further refined in a third wave of analysis to create the five 'final themes' and their sub-themes. These final themes focused on the ADL performance and associated AT use of people with dementia in community and care home locations. They also included some findings on the institutionalisation decision. As the case studies were exploratory and qualitative in nature, there were no hypotheses to be tested. In thematic analysis there is no aim to produce a theory of AT use, as is the purpose of other types of qualitative data analysis such as grounded theory (Braun and Clarke, 2006). Rather, the intention was to identify common and unique experiences of ADL disability and AT use among people with dementia (Stavros and Westberg, 2009, Vaismoradi et al., 2013).

7.7: Changes based on a pilot study

A pilot study was conducted in 2011 at one of the care homes to test the Stage One and Stage Two research methods. In this first version of the study design, care records were viewed only by the

keyworker during Stage One. Data were then collected through conversations with the keyworker. Although this method of data collection produced accurate and up-to-date information about a resident, keyworkers were both pushed for time and unsure as to which information was relevant. Furthermore, as the same keyworker later participated in an in-depth interview about the resident, they repeated some of the information. As such, the study design was altered for this thesis to enable the researcher to map the care record alone; this meant that permission to view the record was needed from the resident. As this then fell under the remit of the MCA, ethical approval from SCREC was necessary.

Another amendment to the design of the research strategy based on the pilot study was to ensure that some spouses were interviewed. This was because all family informants in the pilot study were of a younger generation to the residents, and had not lived with them prior to their institutionalisation. It was anticipated that spouses may have different experiences of providing community-based care for ADLs, and negotiating AT use with people with dementia. However, in actuality only one spouse was able to be interviewed for this final study.

7.8: Chapter 7 summary

In this chapter, the in-depth case study design was detailed and justified. The ethical and legal considerations made by the researcher to gain ethical approval and ensure the project did no harm to participants were presented. The methods for Stage One and Stage Two of data collection were detailed, and the analyses conducted on the resulting data were described. A short description of the pilot study indicated the changes that were made to the project design. Observations resulting from the care record contents and vignettes are presented in Chapter 8, and the full case studies and cross-case comparison are presented in Chapter 9.

Chapter 8: Stage One vignettes

In this chapter, the findings from Stage One of data collection are presented. For Stage One, relevant data were mapped from the care records of residents in the three care homes. Only residents who had a clinical diagnosis of dementia were eligible. The data that were mapped were turned into vignettes, one for each participant. This enabled the clear presentation of each person's ADL disability and their associated AT use. The contents of these vignettes were compared to select participants for Stage Two of data collection. They were also then used as skeletons upon which interview data were added in Stage Two. The care record data were additionally used for an initial exploration of research question 5, which investigated the use of ATs in care homes by and with people with dementia for ADL performance.

The chapter begins with a description of Stage One participants whose care records were mapped. Codes were assigned to each participant to hinder the identification of residents. Their gender, type of dementia they were diagnosed with, and time since diagnosis, if known, are presented. A description of the care record contents follows. An organisational framework was created to categorise the plethora of documents and forms contained in each care record. This framework also aided the creation and structure of the vignettes related to each resident.

These vignettes provided an initial means of understanding the ADL performance of each participant. In the following four sub-sections of this chapter, patterns observed in the vignette data are discussed. The first two sub-sections present patterns concerning what is known about residents' ADL disability and associated use of ATs. To summarise: residents with dementia were monitored by carers throughout ADLs for safety reasons; immobility affected all aspects of care home life; and co-morbidities played a significant role in ADL disability. Incontinence was experienced by all but one resident. The most commonly used ATs were for mobility difficulties. Few residents used ATs for grooming. Moreover, AT use was temporary and dependent on the improvement or progression of the resident's condition. Resistance to ATs was common among the residents; dementia limited their ability to understand the consequences of not using devices. The third sub-section presents patterns identified from the triangulation of vignette data with the care home descriptions previously presented in Chapter 7. Findings suggested that staff preferences and barriers to use of certain ATs affected presence and use of devices in the care homes. It was felt that staff preferences may be as important a factor in AT use as the cognitive and physical functional limitations of the resident with dementia. In the fourth sub-section of observed patterns, a critique

of the use of care record mapping is presented. Overall, care record data made important initial contributions to the understanding of ATs used in care homes for ADLs. However, they were an incomplete source of information and did not enable the researcher to fully explore this study's research questions. All four patterns of observations build a case for more detailed data to be collected from key informants of Stage One participants during Stage Two.

In the final section of this chapter, a key change to the design of this study is described. Initially, the design included the selection of individuals, based on the Stage One vignettes, to elicit multiple case studies in Stage Two. However, there were high drop-out rates observed during Stage One participant recruitment. Drop-outs were attributed to: resident death and illness, residents leaving the care home, and the protracted capacity-to-consent assessment and Personal Consultee procedure. To account for drop-out of potential participants in Stage Two recruitment, it was decided to invite the key informants of all 16 vignette participants to be interviewed. Brief details of the Stage One participants are presented below.

8.1: Stage One participants

The numbers of potential participants and the drop-out rates in each care home during each step of Stage One recruitment were outlined in Chapter 7. This information is shown in the Stage One flowcharts in Appendix 4. Sixteen care records were mapped in total. Table 6 below shows details of the residents. Codes were assigned to mask the residents' names: 'Case A', 'Case B', and so on. Fifteen of the 16 residents were female. Two participants resided in Care home #1, six in Care home #2, and eight in Care home #3. Thus, 50% of the participants resided in one care home. All of the residents had AD or VaD (unless it was unclear or unspecified in the care record). Some of the care records held details of when the person was diagnosed; none included how the diagnosis was made or by whom. Of those for whom a date was included, time since diagnosis ranged from three to five years and up to 14 years. Case G had been diagnosed for the least amount of time at either three or five years (there were inconsistencies within the care record). At the time of data collection she was mobile, received help only with washing and grooming ADLs, and her main cognitive impairments were in the areas of recall, language, and lack of insight into her disabilities. By comparison, Case L had been diagnosed for the longest time at 14 years. Case L was described in the care record as bewildered by her surroundings at all times, completely immobile, unable to verbalise her needs, and requiring carer assistance with all ADLs. Although, as described in Chapter 7, one resident of the

16 was able to provide their own capacity-to-consent in the study, this is not indicated in Table 6 to prevent potential identification.

Table 6: Details of residents whose care records were mapped in Stage One

Resident	Gender	Care home	Diagnosis	Time since diagnosis
Case A	Female	Care home #1	VaD	7 years
Case B	Female	Care home #2	VaD	Unspecified in record
Case C	Male	Care home #2	VaD	12 years
Case D	Female	Care home #2	VaD	Unspecified in record
Case E	Female	Care home #3	AD	6 years
Case F	Female	Care home #3	VaD	Unspecified in record
Case G	Female	Care home #3	AD	3 or 5 years
Case H	Female	Care home #3	VaD	Unspecified in record
Case I	Female	Care home #3	AD	11 years
Case J	Female	Care home #3	VaD	6 years
Case K	Female	Care home #1	VaD	Unspecified in record
Case L	Female	Care home #2	AD	14 years
Case M	Female	Care home #2	Mixed dementia (AD and VaD)	7 years
Case N	Female	Care home #2	Unclear: AD or VaD	5 years
Case O	Female	Care home #3	AD	8 years
Case P	Female	Care home #3	Unspecified in record	Unspecified in record

Key: AD = Alzheimer's disease, VaD = Vascular dementia

8.2: Care record contents

In this section, the documents and forms that formed the contents of the care records are described. These are displayed using an organisational framework that was created by the researcher to aid analysis. Prior to Stage One fieldwork, it was expected that each care record would contain relevant data on: the resident with dementia's ability to conduct ADLs; the human and technological assistance given for each ADL; and any environmental modifications that supported ADL performance. A second expectation was that care records would contain the same types of information for each resident, thus enabling purposive selection into Stage Two of this study. However, during fieldwork it became apparent that some records had missing information that should have been present as standard. This is discussed in more detail in sub-section 8.4.4. There were some concessions concerning missing data; for example, not all residents had a Bed-Rails Consent Form if these were not yet necessary.

Nevertheless, each care record held a plethora of data about each resident. It took the researcher about three hours per care record to map relevant information. A list of the 60+ forms and documents within the care records is presented in the third column of Table 7 below. The first two

columns of Table 7 display the organisational framework (categories and sub-categories) created by the researcher to organise the wealth of forms and documents in each care record. This organisational framework enabled a clear and legible presentation of the contents to both the researcher and reader. Categories and sub-categories were created based on the type of information collected within the documents and forms. The main categories were: details about the resident as they entered the care home; the resident's social care needs; their healthcare needs; and forward-planning for end of life care. A final category grouped any miscellaneous and on-going documents that appeared not to fit into the other categories. Each category is discussed below.

The first category, 'New resident details', was created based on data collected on each person at the point of their entry to their care home. Such data appeared to be collected to ensure a safe, comfortable, and legal relocation. In the first sub-category, 'Prior life', information was collected about the person's known preferences for care, their likes and dislikes (for example, food they particularly enjoyed), and their life prior to entering the care home. These documents and forms were intended to provide the care home staff with ideas of appropriate topics of conversation. The information could also aid employees' understanding and interpretation of the resident's behaviours (Burke, 2010, Innes, 2009, Vittoria, 1998). It had been anticipated that the Life History Form and Pre-Admission Document would detail the reason for institutionalisation. Such data would aid exploration of research question 4 concerning the tipping points for care relocation and whether AT use was involved in the decision. However, only one of the 16 care records described the reason for institutionalisation. For the second sub-category, 'Safety', the Missing Persons Form and the Fire Evacuation Form collected safety data at the point of entry to the home. For example, the former held a detailed description of the physical appearance of the resident in the event of being lost. These two documents were a good initial source of information on the resident's immobility and the extent of human and technological help he or she would need in an emergency, such as whether they would need to be transferred to a stretcher using a hoist. The third sub-category, 'Legalities', contained information to demonstrate the care home had complied with relevant legislation at the time of the relocation. These documents recorded whether the resident had consented to relocate, or that the decision had been made in the person's best interests.

Table 7: Organisational framework to categorise care record contents

Category	Sub-categories	Care record document or form
New resident details	Prior life	Pre-Admission Document; Life History Form divided into childhood and adolescence, young adulthood, middle age and later years; Special Things and Important Dates Form; Important People Chart; Inventory Form to list the personal items they relocated to the care home with
	Safety	Missing Persons Form; Fire Evacuation Form
	Legalities	Consent to Care and Treatment Form; Photography Consent Form; Mental Capacity Assessment; Deprivation of Liberty Safeguards Checklist; Rights Form; Safeguarding Form
Social care needs	Overall care plan	Care Plan for Specific Needs; Care Assessment and Life Plan; Dependency Tool which listed the ADLs and indicated the resident's level of need for these tasks, plus a Dependency Tool Summary and resulting Action Plan which included how many staff and which ATs the person needed for each task; Care Plan Review which was conducted at set times
	Mobility	Manual Handling Risk Assessment; STRATIFY (St. Thomas' Risk Assessment Tool in Falling Elderly Inpatients) Assessment; Physiotherapist's Report; Mobility Form; Bed-Rail Consent Form
	Dressing	Dressing Form; Controlling Body Temperature Form
	Nutrition	MUST (Malnutrition Universal Screening Tool) Assessment; Fluid Balance Form; Nutrition Form
	Personal hygiene	Personal Hygiene Form for washing and bathing
	Continence	Elimination Form; Bristol Stool Form Scale to monitor the consistency of faeces
	Psychological state	Anxiety Form; Depression Form; Activity, Social Care, Well-being and Engagement Form; Mental Health and Well-being Form
	Behaviour	Behaviour Form; Behaviour Tracking Form; Orientation Form; Communication Form
	Safety	Accident Forms; Hazardous Substances Assessment
	Other	Spirituality Form; Expressing Sexuality Form; Night Care and Sleep Form
Healthcare needs	Condition	Long and Short Term Medical Conditions Form; Weight/Blood Pressure Monitoring Form; Pain/Symptom Control Form; Abbey Pain Scale for Dementia; Breathing Form
	Skin integrity	Waterlow Assessment to measure the resident's skin integrity and their risk of pressure sores; General Body Map; Pressure Ulcer/Wound Body Map; Wound Assessment Form; Skin Integrity Form
	Medication	Medication Form
	Professionals	Healthcare Contacts Sheet which also noted their keyworker; Appointments Record
End of life		Preparing for End of Life; Respite Care Plan; End of Life Care Plan; Do Not Resuscitate (DNR) Form
On-going		Daily Diary

In the second category, 'Social care needs', forms and documents recorded the person's ADL disability and the assistance provided. First, the general social care and action plans were collated in the 'Overall care plan' sub-category. Each care record had a Care Plan for Specific Needs which had been written on the person's entry to the care home and updated at regular intervals. This, and a corresponding Dependency Tool, detailed the human and technological assistance required to support the resident to perform each of the ADLs of interest to this research. Sub-categories were then created to categorise the forms and documents under each ADL. For example, a Dressing Form and Controlling Body Temperature Form were in the ADL sub-category: 'Dressing'. Additional sub-categories collated evidence on the person's mobility, psychological state, and challenging behaviours. These could all give useful baseline information on the person's daily life, ADL disability, and associated AT use. The 'Safety' sub-category under 'Social care needs' included a risk assessment for hazardous substances; for instance, Case K had one for her denture cleaning solution. Accidents were also recorded here. These two documents sometimes helped to indicate the person's frailty, ADL performance, and even associated AT use. For example, some accident forms recorded that residents had fallen after forgetting to use their walking ATs. Three miscellaneous documents that still fit under the category of 'Social care needs' were included in the final sub-category, 'Other'. These indicated the extent to which the person needed help to manage their spirituality, sexuality and other private matters, night-time routine, and sleep. It was in this 'Social care needs' category that the bulk of relevant data were mapped.

The third category of care record contents related to 'Healthcare needs'. The first of the four sub-categories concerned the person's 'Condition', which included their co-morbidities, pain, and breathing. Given that this research was also interested in the extent to which other conditions impacted upon ADL disability, such information was important. Five forms collected information on 'Skin integrity'. These indicated whether the person was at risk of developing pressure sores (for example because of incontinence, immobility, or cellulitis), and whether any associated preventive and treating actions were recorded. This information provided relevant data on the person's functional limitations and ATs used to manage the quality of their skin, such as blow-up foot elevators. Information in the 'Medication' sub-category indicated what treatments the resident had to manage their co-morbidities; these data were mapped to explore whether some treatments affected the person's ability to perform ADLs. Finally, some information on 'Professionals' signified whether residents continued to keep their community healthcare professionals (such as their GP), or used others post-relocation. This information gave a broad indication of the management of some

ADLs and functional limitations in care home locations. For example, whether a resident would cut their own toenails or instead have regular visits from a podiatrist linked to the care home.

There were four types of forms relating to palliative care or 'End of life', indicated in the fourth category of the organisational framework. Thirteen residents had a Do Not Resuscitate (DNR) form ready in the care record. The reasons were usually because Cardio-Pulmonary Resuscitation (CPR) would cause immense damage to the person's body, which would lead to a poor quality of life. These provided the researcher with some idea of the frailty of each resident, and could be linked to information on their ADL performance.

An 'On-going' document was placed into a fifth category. The care records contained a Daily Diary which recorded, for example, whether the person had slept well, or needed assistance to eat lunch that day. These usually dated back a few months, and were a useful source of data on current daily life including the person's ADL disability and AT use.

The organisational framework was created to categorise care record contents for clear display and understanding. The framework also assisted the formation of a structured vignette for each resident. Having identically-ordered vignettes aided purposive selection of participants for Stage Two of data collection. They also enabled some meaningful preliminary observations of Stage One data to be made. The organisational framework is a practical output of the experience of mapping data from care records and may be used as a model for future research design and analysis. This is discussed further in Chapter 10. Below, the vignette structure is described.

8.3: Structure of the vignettes created from care record data

The data mapped from each care record were turned into vignettes to display in prose the relevant information about a person's experience of life with dementia, particularly their ADL disability and related AT use. Vignettes enabled the presentation of data in an organised and consistent way, using key factors relating to each individual's ADL disability. The primary objective of this procedure was to create base data from which to compare and then select residents for a variety of case studies on ATs used, and not used, for ADL performance. The actual selection of participants is further discussed in section 8.5.

The vignettes were written in the present tense to denote the person's current abilities at the time the data were collected in the spring and summer of 2013. Therefore, any information relating to year; for example, 'Case A is a female in her early 80s. She has VaD, which was diagnosed seven years ago' reflects the situation at the time of data collection. Exact dates are not presented in this thesis to prevent identification of care home residents. The vignettes for Cases A through P are provided in Appendix 5.

The structure of the vignettes was based on the categories and sub-categories identified in the organisational framework created to legibly display the care record contents, which was presented in section 8.2. Specifically, the vignettes were structured by chronology and by type of ADL into the following sections: 'Pre-relocation', 'Relocation, capacity and care home life', 'Medical and sensory conditions', 'Mobility and orientation', 'Washing, bathing and skin integrity', 'Grooming', 'Dressing and body temperature', 'Bathroom use and continence', 'Eating', and 'End of life plan'. They were categorised as such to aid identification of participants' ADL performance and associated human and technological assistance. The structure enabled a holistic understanding of ADL performance, as information could be linked within the vignette to their cognitive and physical impairments, co-morbidities, and to the wider context of the environment (such as care home design). Comparisons between participants were also possible due to the structure. For example, both Case A and Case E resided in Care home #1. The 'Washing, bathing and skin integrity' section of the vignettes indicated that Case E required intermittent, and sometimes complete, physical human support to wash. She also frequently used a bath hoist. Case A, however, could usually wash herself without help, although sometimes required verbal prompting. She could use the walk-in shower, and had the steps of showering on a wall poster to help her. Thus, data could be compared between the vignettes to understand how performance of the same ADL differed among people with dementia who resided in the same environment. Then, participants could be selected to represent a variety of disabilities, histories, demographics, and personalities for Stage Two case studies.

It is acknowledged however, that although the vignettes were structured by ADL, impairments in one ADL can impact on others. For example, the Waterlow score indicates the person's likelihood of developing pressure sores and thus affects their skin integrity, so is presented in the 'Washing, bathing and skin integrity' section of each vignette. However, skin integrity can also be affected by the person's weight (yet weight data was placed into the 'Eating' section); co-morbidities such as cellulitis (found in the 'Co-morbidities' section); fluid intake ('Eating' section); immobility ('Mobility and orientation' section); or incontinence ('Bathroom use and continence' section). Thus, a

discussion of skin integrity could be linked to any number of the vignette categories. To further illustrate, a person may be perceived as incontinent because of bladder or sphincter weakness, whereas in fact their incontinence was caused by either the inability to perceive the need to evacuate their bowels, the inability to communicate this need to others, their disorientation when locating a toilet, or immobility. Again, a discussion of their incontinence could be linked to multiple cognitive and physical impairments and performance of other ADLs. Therefore, understanding ADL impairment for people with dementia does not fit neatly into separate boxes.

The comparison of vignette data was anticipated not only to aid selection for Stage Two, but to enable initial exploration for research question 5, concerning ADL performance and related AT use in care home settings. Thus, two key gaps identified in the scoping review could begin to be addressed: the task-specific difficulties people with dementia have when performing ADLs (Chapter 3), and when and how ATs are used in care homes for residents with dementia (Chapter 5). Some key patterns were observed in an exploration of vignette data; these are presented below.

8.4: Patterns observed from the vignette data

There were four patterns observed in the data once the vignettes were created, and while they were being used to identify and select participants for full case studies in Stage Two. Each pattern is presented in the following four sub-sections. The first pattern relates to the ADL disabilities of residents. The second pattern concerns what was known about the ATs that were used by the residents with dementia. The third observed pattern relates to the care home environments. This brings together the descriptions of care homes previously presented in Chapter 7 with vignette data. The fourth observed pattern in the vignette data concerns three main issues with using care record data for this study.

8.4.1: Residents' difficulty performing ADLs

Overall, the care record contents demonstrated that living well in a care home is about much more than being able to perform ADLs. Care home staff were not only responsible for meeting these basic ADL needs, but for ensuring the legal, health, emotional, and spiritual well-being of residents in their care (Maslow, 1943, Vittoria, 1998). Although quality of life is multi-faceted, only ADL performance was the focus of this study. The data did not indicate whether the individuals arrived at the care home with ADL impairments, but did demonstrate that all of the ADLs under investigation were impaired to some extent among Stage One participants while living in their care homes. Residents'

performance of ADLs is presented in this sub-section. However, first there were four general patterns that seemed to set the context for ADL performance. These related to the need for carer monitoring during ADLs; the opportunities staff presented to enable self-performance of tasks; the contributing role of physical and psychological co-morbidities on ADL performance; and the substantial role of immobility which influenced the disability experienced.

All of the participants were at a stage where, at the very least, visual monitoring during ADLs and general daily life was required for their safety. That is, those who needed the least assistance still usually required supervision from a carer to watch them to ensure tasks were fulfilled appropriately, even at the expense of privacy (Rosenberg et al., 2012). Those with severe dementia required complete assistance with all aspects of daily life as they became immobile, lost communication skills, and became unable to plan and sequence actions (Lawrence and Jette, 1996).

Yet, the data also demonstrated that care home staff provided multiple opportunities for residents to perform tasks and activities for themselves, when appropriate. For example, Case A was able to use the kitchenette to make cups of tea alone, although staff always ensured the kettle was already filled with water, and labels were on items. These strategies helped Case A to maintain some sense of independence and liberty, albeit also contributed to her delusion that she worked at Care home #1. However, Case A could only make a cup of tea on her own because the environment, the design of the dementia-friendly kitchenette, enabled this. The only task whereby opportunities for residents to perform activities alone were not promoted at all concerned the administration of medication in the care homes: all residents were dependent on the nursing staff of the homes to provide this at the appropriate time. Legally of course, staff cannot force residents to take their medication, but owing to memory loss associated with dementia there was concern that some residents would forget their pills if they were to self-manage their treatments. Subsequently, there was no recorded use of medication-reminder ATs in care records.

The vignette data indicated that the residents with dementia had physical, sensory, and psychological co-morbidities which contributed to poor ADL performance. Almost all had poor hearing or sight, and arthritis in particular caused significant pain and stiffness which necessitated carer or technological assistance with daily activities. The symptoms of dementia further exacerbated co-morbid symptoms; for example, Case F's glaucoma worsened as she could not remember to stop rubbing her eyes, and Case P refused to wear hearing aids because she lacked insight into her deafness. The psychological consequences of dementia were extremely apparent in

the residents. Ten of the 16 displayed anxiety and associated symptoms and behaviours such as bewilderment and agitation, which impacted upon ADL performance. For example, Case B was anxious about her incontinence. Case M would 'fight back' when receiving washing and toileting assistance from staff, although once the task was over she would calm down and request a kiss from the carers. Some residents were on antipsychotic medication to manage their anxiety. Depression was prevalent in seven of the 16, with tearfulness, being withdrawn, and refusing to eat being common behaviours. Verbal and physical aggression, suspicion, paranoia, and associated accusations were also indicated in the care records. These behaviours hindered carers' assistance with ADLs. Bewilderment and disorientation to time, place, and person were displayed by most residents, and were more apparent in those who had progressed to a later stage of dementia. Room signs and labels were always in place, but eventually became un-noticed or indecipherable to residents.

All of the residents had at least some immobility. Even Case G, who had the most functional capacity of the participants, was prone to falls. Again, for some residents poor mobility was attributed to a co-morbid condition such as arthritis or stroke. How the functional limitation of immobility contributed to impaired performance of all of the ADLs was explained in the disablement process model (Nagi, 1965, Verbrugge and Jette, 1994) in Chapters 3 and 4. As many participants used ATs to manage their immobility separately to ATs for ADLs, mobility-related ATs were subsequently included in this investigation of technologies used by people with dementia. However, although the care records detailed the mobility-related ATs that the person used such as wheelchairs, slide-sheets, and stand-aid hoists, they did not detail: how the person's bodily movements had become affected; when they began to experience immobility; and how it changed over time. Therefore, the extent to which dementia led to this functional limitation could not be determined by the care record data alone. Generally, the more physical functional limitations the person had, the more ADL assistance was given to them.

Concerning the ADLs under investigation in this research, the performance of washing and bathing seemed quite determined by the presence of co-morbidities and immobility. Arthritis in particular was a big indicator of the extent to which human and technological assistance was required with washing and bathing. The effects of cognitive impairments were more apparent during washing and bathing, when residents were confused about the steps needed to wash or displayed resistance and aggression. This finding was reflected in previous studies as most research attention has been given to resistant behaviours when bathing, rather than the performance of the task (Dunn et al., 2002, Namazi and Johnson, 1996, Sloane et al., 1995). Case A was the only Stage One participant who was

able to shower on her own; however, even she required checking by a carer afterwards (sometimes during) to ensure she had completed the task appropriately.

Fifteen of the 16 participants had some type of incontinence. This either related to inability to control the bladder or bowels (Hägglund, 2010), or because they eliminated in an incorrect location (International Longevity Centre-UK, 2013), such as Case O who would self-evacuate her bowels with her hands and hide the contents. Those with poor sphincter control used continence pads, but the care records did not detail whether the incontinence was caused by cognitive or physical functional limitations, or the environment. The sixteenth resident, Case A, had toileting disability relating only to physical functional limitation; her arthritis meant she required a raised and winged toilet seat to aid sitting. Those with greatest immobility also used ATs to aid toileting, such as stand-aid hoists to transfer onto bedroom commodes.

Eating was one of the more varied ADLs in terms of the assistance each resident needed. All required help with tasks that required wrist and hand strength and flexibility, such as opening bottles and cutting food. Those residents in the less severe stage of dementia could feed themselves using standard cutlery, but still required some verbal prompting (Amella et al., 2008). Others whom had progressed in their cognitive and physical functional limitations took pureed food from a spoon which was administered to them by a carer. It seemed that the decision to present food in liquidised form usually followed the display of behaviours such as spitting out food, forgetting or refusing to swallow, and always after recommendation by a SALT (Speech and Language Therapist for swallowing disorders). There was no acknowledgement in the care record of why problems with eating occurred, or whether the environment contributed to poor eating behaviour (Griffin, 1995, Slaughter et al., 2011). The individuals with pureed diets also had thickeners in their fluids to prevent accidental aspiration of liquid. Fluid thickeners were considered an AT in this study. Observations relating to ATs used by residents are given particular attention below.

8.4.2: Assistive Technologies used by and with residents

In this sub-section, patterns concerning the ATs used in the care homes are discussed. These were: that the majority of ATs were to aid immobility; most were not dementia-specific in design; they were not used by residents with dementia alone; ATs were not used for the performance of certain ADLs; use of most ATs was temporary depending on the person's condition; and refusal to use ATs was common among the residents with dementia owing to lack of insight into their condition. These are discussed in more detail below.

The ATs used by each care home resident are listed below in Table 8. As can be seen, all residents used ATs. The majority of the devices were for immobility and transferring actions, although continence pads and fluid thickeners were also common. None of the devices used, with the exception of room signs and item labels, were dementia-specific but instead general devices that could be used by any care home resident (Passini et al., 2000). Dementia-specific environmental modifications included colour-contrasting toilet seats in the main corridor bathrooms, and some colour contrast in hallways, for example to enable the hand-rail to be seen.

When looking at the actual usage of present ATs, it seemed that nearly all of the devices, except for floor sensors next to beds, required the input of at least one carer for use. Whether this did or did not increase staff workload (Boger et al., 2006, Mihailidis et al., 2008) was of interest for Stage Two of data collection. Thus, the data suggested that ATs did not substitute for, but only supplemented, carer assistance (Agree et al., 2005). However, this raised a further question concerning whether the residents did indeed use some ATs alone, but only those that carers used with them were written in the care records. Some similar inconsistencies are discussed in sub-section 8.4.4.

It was observed from the vignette data that ATs were not used for grooming ADL, excluding typical devices such as a toothbrush or hairdryer. Dressing was another ADL where assistance was completely human until a resident became bed-bound. Then, slide-sheets were used to move the body to prevent harm to residents and carers as a result of manual handling. This indicated that ATs were only used once safety became a priority issue. Indeed, it seemed that for immobility and other ADLs, ATs were only used when safety was a concern: whether to prevent falls and injury, skin breakdown, or choking hazards. Further exploration of this in Stage Two was needed.

Table 8: Assistive Technologies used by participants in the care homes, according to their care record data

Resident	Assistive Technologies used currently or historically, as indicated in the care record
Case A	Walking stick, wet-room for showering, call-bell by bed, raised and winged toilet seat, instructions on what to do with dirty laundry, spectacles
Case B	Wheelchair with lap-belt, nursing bed, bed-rails with full-length bumpers, call-bell by bed, continence pads, commode, hearing aid
Case C	Walking frame, wheelchair, stand-aid hoist with handling belt, bath hoist, nursing bed, bed-rails - inconsistency about bumpers, call-bell by bed, slide sheet, continence pads, fluid thickener in drinks
Case D	Water-chair with lap belt, stretcher, stand-aid hoist with small sling, nursing bed, pressure-relieving mattress, bed-rails with bumpers, call-bell by bed, slide-sheet, continence pads, nutritional supplement, fluid thickener in drinks, spectacles, hearing aids
Case E	Walking stick, bath hoist, nursing bed, pressure-relieving mattress, call-bell by bed, continence pads, inconsistency about dentures
Case F	Three-wheeled walker, wheelchair, stand-aid hoist with large sling, nursing bed, inconsistency about bed-rails, pressure-relieving mattress, call-bell by bed, slide-sheet, sensor mat next to bed at night, hip-protectors, continence pads, inconsistency about dentures
Case G	Nursing bed, call-bell by bed, sensor mat next to bed at night, continence pads
Case H	Walking frame, wheelchair, stand-aid hoist with sling, nursing bed, call-bell by bed, sensor mat next to bed at night, continence pads, commode, calcium supplement, fluid thickener in drinks, spectacles
Case I	Stand-aid hoist with sling, nursing bed, bed-rails with bumpers, call-bell by bed, slide-sheet, continence pads, one-time catheter, nutritional supplement, fluid thickener in drinks
Case J	Walking stick, walking frame, nursing bed, call-bell by bed, sensor mat next to bed at night, hip protectors, continence pads, commode, spectacles
Case K	Wheelchair when outside Care home #1, orientation signs on bedroom and en-suite, call-bell by bed, sensor mat next to bed at night, blow-up leg support, continence pads, commode, lightweight mug with a large handle, spectacles, dentures
Case L	Water-chair, stand-aid hoist - inconsistency of sling size, bath hoist, nursing bed, bed-rails with bumpers, pressure-relieving mattress, call-bell by bed, slide-sheet
Case M	Walking frame, handling belt when walking, turntable to transfer, nursing bed, pressure-relieving mattress with air-compressor unit, bed-rails with bumpers, call-bell by bed, slide-sheet, clock in constant view, continence pads, commode, multiple nutritional supplements
Case N	Water-chair, stand-aid hoist with sling, nursing bed, pressure-relieving mattress with air-compressor unit, bed-rails with bumpers, call-bell by bed, slide-sheet, continence pads, commode
Case O	Walking stick, nursing bed, call-bell by bed, sensor mat next to bed at night, nutritional supplement
Case P	Wheelchair, pressure-relieving cushion for sacrum, stand-aid hoist with sling, nursing bed, bed-rails with bumpers, pressure-relieving mattress, call-bell by bed, slide-sheet, hip-protectors, continence pads, fluid thickener in drinks

Use of ATs appeared temporary depending on the person's condition and whether it improved or worsened. For example, Case L used a blow-up foot elevator in bed only while a heel pressure sore healed, and Case I had a catheter until a sacrum pressure sore healed. Alternatively, and more commonly, a person used a device but then 'upgraded' to an AT that provided even more support as their disability progressed. For example, first he or she used a walking stick; as their cognitive and physical impairments increased a walking frame would be used (sometimes with carers aiding balance); and over time he or she used a wheelchair or water-chair plus transferring hoists. Eventually he or she became completely immobile and bed-bound, and only used a hoist for being weighed or sometimes to be placed onto a commode. This raises the query whether these residents were already people with major underlying disability and thus the corresponding post-AT residual disability was too great to prevent further decline (Taati et al., 2011, Verbrugge and Jette, 1994); or whether reliance on a device or carer, such as to support immobility, itself contributed to increased disability (Barzel, 1991, Faulkner, 2001, Foy and Mitchell, 1991, Pew and Van Hemel, 2004). Due to lack of data on the care records concerning the person's life pre-institutionalisation, a comparison between community and care home AT use could not be made from Stage One data alone.

Some patterns concerning refusal to use devices were observed. Case A would not use her walking stick, and as aforementioned Case P would not put in her hearing aids. It was noted in Case J's care record that she would be angry if bed-rails were put in place, so none were used. Case O was frightened of the bath hoist and had to be persuaded to 'go swimming'; such unfamiliar devices have been found to result in resistive or aggressive behaviours (Day et al., 2000, Namazi and Johnson, 1996). Alternatively, it may be that the residents felt that device use would contribute to their being viewed by others as dependent and fragile (Bentley et al., 2014, Demiris and Hensel, 2009). Further exploration of use, non-use, and refusal to use ATs by residents with dementia was desired to understand these behaviours. Indeed, it was felt that the vignettes, while a useful source of data, could provide no context to ATs used by and with people with dementia (Innes, 2009). That is, care record data could report AT use, but not explore thought processes behind a decision to use an AT, or describe the complex phenomena of beginning to use and maintaining its use with a person with dementia. It also became apparent during Stage One of data collection that there some problems using care records as a sole source of data (see sub-section 8.4.4).

In summary, there are a wide variety of ATs on the market that could be used in care home settings to support people with dementia to perform ADLs alone or in conjunction with a carer. Yet, these observations of ATs used by Stage One participants indicated that the majority of devices were to

support immobility. For some ADLs, such as grooming and dressing, ATs were rarely used. No ATs for ADLs were dementia-specific. This leads to questions concerning why some ATs were used and others were not, and how the physical and attitudinal environment of care home design and staff influenced device use. For example, as staff members typically identified opportunities for self-performance of ADLs and also for potential use of ATs, whether they had some conscious or unconscious barriers to particular technologies. As carers' preferences of AT use were to be explored for research question 3 and care home AT use for research question 5, the issue of environment was to be considered further when analysing carers' interview data after Stage Two of data collection.

8.4.3: Care home environments

Descriptions of the three care homes were presented in Chapter 7. They illustrated the context within which residents lived, and in which they performed ADLs and used ATs. This is important because the disablement process model which underpins this thesis states that ADL disability only occurs when bodily functional limitations are performed in unsupportive environments (Allen et al., 2001, Nagi, 1965, Nagi, 1991, Jette, 2009). Below, these descriptions are amalgamated with the vignette data, to provide some initial observations about the design of the care homes to support ADL performance, and whether AT use in these locations was supported. These had to focus on more public areas of the homes: corridor bathrooms (to support washing and toileting) and dining rooms (eating), as grooming and dressing activities were performed in bedrooms.

Key features of the homes were described to indicate how they were designed to support, or were adapted to enhance support, ADL performance. Care home #1 was very specifically adapted for residents with dementia, with a dedicated wing for those with cognitive impairments. A dementia-friendly and supportive environment had clearly been considered, there were: colour contrasts to aid safe walking; 'front doors' for bedrooms; a dedicated reminiscence room; and room-signs and labels on items. Care homes #2 and #3 were adapting their environments with similar styles at the time of data collection. However, whilst these adaptations enabled residents to feel more at home and aimed to prevent disorientation, these did not specifically support the basic ADL tasks. Instead, vignette data indicated that human carers were involved in almost all ADLs once support was needed. The only ADL exception seemed to be eating, when some residents used eating ATs alone.

All of the care homes had kitchenettes on their wings within which residents could make a cup of tea on their own. However, Care home #1 was the only one of the three homes to have item labels to encourage people with dementia to make their own drinks. Subsequently, Case A, who lived there,

was the only one of all the Stage One participants to make her own cup of tea. Care home #1 was also unique with its support of eating ADL for residents with dementia. There, residents on the dementia wing were seated café-style at small round tables. They were encouraged to lay the table if they could. The small dining room, coupled with old songs on the radio, encouraged a focus on the food and enabled their keyworkers to more effectively provide supervision, verbal prompting, and physical assistance with eating. The other two care homes still had dedicated eating spaces for residents on each wing, but these were not dementia-specific. Fewer formal carers per wing at Care homes #2 and #3 meant that less human assistance was available per resident.

Most bathrooms in the three care homes were wet-room style, with the exception of some small toilets in reception areas for visitors. This style of bathroom enabled residents to shower more easily, and to sit on shower seats or stools to aid washing if necessary. Care home #1 was the only care home to have a list of the steps to shower on the wall. This was for Case A, who was still able to perform these actions on her own. Most corridor bathrooms were observed to have a dark blue toilet seat in order to stand out more clearly from the pale surroundings, though not all the en-suites had colour contrast. Care home #2 was unique in comparison to the other two care homes in that it had only mechanical baths and no showering facilities at the time of data collection. This was a large property, but with only two bathrooms to assist residents to have supported baths. However, it was not known whether the en-suite facilities of mobile residents had baths; mechanical or non-mechanical. They did not have showers. Informal discussions with staff indicated that residents typically had strip-washes or bed baths in their bedrooms and a traditional bath once weekly, owing to demand for the bath hoist. With only care home observations and care record data to infer from, it was not known the extent to which residents with dementia were free to make preferred choices of how and when to wash. Thus, more exploration on how the care homes supported washing ADL was required for Stage Two of data collection. From informal discussion with the formal carers, these coloured bathroom adaptations were not always available. There seemed to be some culture among employees of the homes of being happy with whatever item could be obtained at the time, and not pushing to obtain the most supportive, dementia-specific AT.

Indeed, field notes from conversations with the staff members did indicate that employees could suggest for new ATs to be used when they perceived a potential need. However, care record data suggested that perhaps proposals for new devices were restricted to the extent of carers' knowledge about what was available. For example, the comparison of vignettes indicated that no ATs for grooming or dressing (beyond a slide-sheet when the person was immobile) were used. If staff were

not aware that devices existed, then of course they could not perceive an AT opportunity. Yet, there were AT booklets in the reception areas of each care home. It is possible that: the environment of the care homes was such that employees had no time to research the devices that existed; ATs were considered an unnecessary expenditure given that carers were present; or residents preferred to be dressed and groomed with human assistance. It is also possible that ATs for these ADLs had been used, but abandoned. However, if so, these should have been recorded in the care records.

8.4.4: Care records an incomplete source of data

The patterns observed from the 16 vignettes produced an initial illustration of care home life with regards to ADL difficulties and the types of ATs used by residents with dementia. The mapping exercise showed that residents varied in terms of their communication; some were able to convey their needs to carers, whereas others had impaired speech or body language. It highlighted the differences between residents concerning ADL performance, but crucially demonstrated that they received regular human or technological assistance with at least one aspect of ADL disability. However, although the care records provided useful background to each resident's ADL needs, they were an incomplete source of data for the research questions of this study. The issues concerned: three types of inconsistencies within and between care record data; vital missing information necessary for this research; and a lack of sufficiently detailed description of the task-specific difficulties to permit detailed analysis. These are discussed below.

The first issue with using care records concerned three types of inconsistencies in relation to: data held on different pages within the care record; data between the care record and the researcher's observations; and out-of-date information in the care record. First, many inconsistencies were observed with respect to the information held within the care record itself. For example, Case K's care record indicated two different relocation dates. There were also inconsistencies as to whether carers did or did not use a slide-sheet to reposition Case F. The second type of inconsistency was between the information contained in the care record and what the researcher observed from her dealings with the gatekeeper or from having met the resident during the capacity-to-consent assessment. For example, Case C's Bed-Rails Assessment stated that he did not need bed-rails because he never moved on his own, yet the researcher had previously observed bed-rails in his bedroom. The third type of inconsistency occurred when data were out-of-date; nearly all of the care records logged an incorrect keyworker because the relevant form had not been updated following staff turnover. These three types of inconsistencies hindered the meaningful understanding of the progression of the resident's dementia, their disabilities, and any AT use since

arriving at the care home. Thus, it was important to build a picture of each person's dementia care using in-depth case studies.

A second issue with using care records was that, for the research topics in this study, vital information was missing. The necessary and recommended forms and documents listed in Table 7 were not present in every care record. Most care records were missing the Life History Form, which was designed to provide essential data on the social networks or caring circumstances of the individual when he or she lived at home, or on the nature of the relocation decision.

Understandably, the rest of the care record contents were focused on the person's life since they moved to the care home and so did not detail the person's difficulties performing ADLs and their AT use prior to institutionalisation. However, this limited the ability to explore the first four research questions of this study, which were concerned with community-based ADL disability and AT use. Therefore, analysis of care record data alone would not meet the study aim.

The third issue was that even information that could contribute to research question 5 of this study, exploring ADL disability and ATs used in care homes, was rarely detailed enough to fully explore the issues under investigation. Descriptions of the person's ability to perform ADLs and the ATs used were present, but there were no specific details on whether, for example, a person's task errors were caused by their physical or cognitive impairment, their environment, or a combination of all three (Verbrugge and Jette, 1994). It was outlined in Chapter 3 that understanding the task-specific difficulties of ADL disability are important in order to design appropriate dementia care services and promote quality of life (Bharucha et al., 2009). The care record data also did not detail: whether the person with dementia chose to use an AT; if it was used by them alone; and the extent of prompting and physical assistance by formal carers. Furthermore, care records did not detail whether family members conducted ADLs with their relative and any associated joint AT use (Schulz et al., 2004). Thus, care records were an insufficiently detailed source of data for analysis in this research. However, the purpose was never to use the mapping exercise as the sole source of data, merely to begin to explore some of the issues and to enable selection of participants for further investigation in Stage Two of data collection.

8.5: Selection of Stage One participants for Stage Two

The original intended main output for Stage One of data collection was to gather baseline information about the ADL disability and associated AT use of care home residents with dementia,

and to use this information to target a variety of individuals for further investigation in full case study format. Examples of seven individuals that were of particular interest based on the data, and thus were intended to be purposively selected for Stage Two of data collection, follow. First, Case C was unique as the only male resident, and the only resident with a living spouse. Case C was also the only resident for whom detailed information on his life history and the institutionalisation decision was contained in the care record; this was attributed to his wife who had completed the Life History Form comprehensively. Furthermore, he was the only resident to use pull-up style of continence pads. As this style is not provided for free by healthcare services (Fader et al., 2008), it was of interest to understand from where these were obtained. Second, the data indicated that Case J's life immediately prior to residing in Care home #3 seemed complicated; a stroke had led to a hospital stay, then she moved to a care home, then to a psychiatric hospital, and then she relocated to Care home #3. The only details on the reason she could not live in the community were 'increased confusion and inability to manage at home', which warranted further exploration. Third, Case K had been fostered as a child and had worked as a mother's helper on a farm for more than 60 years. The care record showed her next of kin as her foster-sister and nephew, but the informal carer in the care record was listed as the son of the woman she worked for on the farm. She had never married. Further, Case K was perceived by her GP as having mild learning disabilities, although never formally diagnosed. It was anticipated that this would be an interesting case study to determine the extent to which her dementia and such perceived co-morbidities impacted upon ADL performance. Fourth and fifth, Case I and Case M were intended to be selected because they had progressed to the severe stage of dementia, were at the end of their lives, and were no longer to be sent to the hospital when ill according to their palliative care plans. Sixth, Case M was also the only resident indicated in the care record as aware of her memory loss. Seventh, Case G was of interest as she had moved to Care home #3 together with her husband. She was to be selected for further exploration on what had led to their joint relocation. Furthermore, Case G appeared to use the fewest ATs in the care home compared to the other residents in Stage One, according to her care record data.

However, as indicated in the flowchart in Appendix 4, following the capacity-to-consent assessment process the total population of 56 eligible care home residents only resulted in 16 vignettes. Due to the high drop-out rate, and some anticipated drop-outs during Stage Two recruitment, it was decided that potential key informants of all of the Stage One participants would be eligible for Stage Two. That is, the informal and formal carers of Cases A to P were to be invited to an interview.

8.6: Chapter 8 summary

The vignettes, created from mapped care record data, provided baseline information concerning the current ADL disability of 16 care home residents with dementia, and the human and technological assistance given to them to aid performance. Difficulty with all ADLs was evidenced, though relevant ATs were not used for all. Notably, grooming and dressing ATs were not used, according to the care record data. The observed patterns among the vignette data began to elicit more questions on whether: this lack of use of some ATs was linked to physical and attitudinal environment within the care homes and lack of knowledge among staff that these devices existed; inability to locate or obtain such devices; or simply that residents preferred human assistance during grooming and dressing. Overall, the findings contributed to initial exploration of research question 5, as they began to show how ATs may be used in care homes to contribute to the daily lives of people with dementia.

However, the care records did not detail when these technologies were and were not used, the perceptions of people with dementia and their informal and formal carers about the use of ATs, nor completely explore how AT use changed over time. It was not known whether any resident had brought an AT with them from home to support their relocation. The care records did not indicate whether family members ever provided ADL assistance in care home locations, and the extent they were involved in decisions about AT use in such locations. Stage Two of data collection was designed to explore these knowledge gaps in greater detail. The details of Stage Two participants, the case studies resulting from the combination of care record and interview data, and analytical comparison of the case studies follow in Chapter 9.

Chapter 9: Stage Two case studies and the cross-case comparison

In this chapter, the case studies and their comparative analysis created from Stage Two of data collection are presented. For Stage Two, interviews with key informants from Stage One residents were conducted. These interviews built on the Stage One vignettes by eliciting more detailed accounts of the person with dementia's ADL disability, and the ATs they used in the community and care home. The interviews also investigated carers' perceptions of the role ATs had in dementia care. The vignette and interview data together yielded a detailed case study of each person with dementia. To explore the research questions more fully, the care record data and interview transcripts were then subject to a cross-case comparison using thematic analysis. This enabled common and unique experiences to be identified.

The chapter begins with a description of Stage Two participants. Codes were assigned to the key informants to prevent their identification. The relationships of informal carers to residents, such as 'daughter' or 'wife', are given. The gender of keyworkers is also indicated. The structure of the case studies then follows. The case studies narrate the life of each resident with dementia, with a particular focus on their ADL difficulty and use of ATs over three time periods: while living in the community; at the time of institutionalisation; and in daily care home life. Case studies were structured using this time sequence and also by ADLs, to ease comparison within and between the case studies. To illustrate: within the case study, the person with dementia's washing disability when they lived at home could be compared to their current washing disability in the care home. Between case studies, the identical structure enabled the community-based washing disability of Case A and Case B to be identified and compared.

In the next section, some discussion is given to the benefits of the interview data for the exploration of AT use over the information contained in the care record. Not only did interview data identify ATs used in the community, but highlighted that many more ATs were used in care homes than previously documented. The remainder of the chapter focuses on the findings of the cross-case comparison. Five final themes and their sub-themes, each relating to a research question of this study, are presented and discussed in turn.

9.1: Stage Two participants

Informal carers and keyworkers of all residents whose care records were mapped in Stage One were invited to be key informant interview participants in Stage Two. The number of potential

participants and associated drop-out rates at each care home (during each step of the interview process) are detailed in Chapter 7 and in the Stage Two flowcharts in Appendix 4. If a family member declined to be interviewed, the keyworker was also not interviewed and the resident was not the focus of a complete case study. If a keyworker could not participate, a different staff member with detailed knowledge of the resident's ADL ability was identified and interviewed.

If residents had multiple main points of contact, an interview invitation was posted to each relevant individual. Some residents had multiple adult children but one was always listed as the main contact. In these situations, interview invitations were posted only to this person, who was asked to indicate if they felt it appropriate for other family members to be interviewed. However, when invitations were sent to these additional potential participants, all declined.

In total, 10 case studies were created from Stage One care record data and interviews from 11 family members and 10 keyworkers. These were the residents coded in Stage One as Case A to Case J. Details of the interview participants are shown below in Table 9. As can be seen, codes were also given to the family members and keyworkers to aid confidentiality. The letter-code of a resident became the same letter-code for the family member and keyworker. For example, Case A's daughter became 'A1' (the first family member interviewed for Case A), and her keyworker became 'K1A' (keyworker number 1, linked to Case A). Case B's daughter became 'B1' (the first family member interviewed for Case B), and her keyworker became 'K2B' (keyworker number 2, linked to Case B).

Table 9: Details of key informants in Stage Two

Resident	Care home	Family member	Keyworker	Keyworker gender
Case A	Care home #1	A1, daughter	K1A	Female
Case B	Care home #2	B1, daughter	K2B	Female
Case C	Care home #2	C1, wife	K3C	Female
Case D	Care home #2	D1, daughter	K4D	Female
Case E	Care home #3	E1, daughter	K5E	Female
Case F	Care home #3	F1, son	K6F	Female
Case G	Care home #3	G1, son	K7G	Female
Case H	Care home #3	H1, daughter	K8H	Female
Case I	Care home #3	I1, niece-in-law	K9I	Female
Case J	Care home #3	J1 and J2, both daughters	K10J	Female

As can be seen from Table 9, all keyworkers were female. No male staff members were keyworkers for the residents who became case studies in Stage Two. The majority of the family members were

female, and were typically adult daughters. Two sons were interviewed: F1 (an only child) and G1 (who perceived his brother would not want to participate in an interview). A sister and brother were both invited for interview for Case H, as both shared caring duties for their mother. The brother attended the family carer consultation meeting at Care home #3 and was present during Case H's capacity-to-consent assessment. He initially accepted an interview, but after cancelled due to illness. His sister speculated, *'He would be uncomfortable talking about the things he does [regarding] the finances'* and perceived that talking about his mother was too stressful for him. Case I had no children, and her nephew advised that it was more appropriate to interview his wife, Case I's niece-in-law, as she had been more involved with Case I's care when she resided in the community. Case J had three daughters who intended to be interviewed together, but on the interview date the third sister had to work. Therefore, only J1 and J2 had a joint interview.

On average, the 10 interviews with informal carers lasted for one hour and 12 minutes. The shortest of these was with F1 at 30 minutes. The longest was with E1 at one hour and 58 minutes; this interview was conducted at her own home rather than in a private room at the care home. The average time of the keyworker interviews was shorter than those for family members, at almost 31 minutes. The shortest of these was with K6F at close to 15 minutes. The longest was with K1A at one hour and 22 minutes.

9.2: Structure of case studies created from Stage One and Stage Two data

The case studies were created by integrating the care record and interview data. The Stage One vignettes acted as skeleton structures upon which the data from Stage Two key informant interviews were added, then refined to create an in-depth case study for each resident. All case studies included some aspects of the life history of each resident, their dementia, their ADL disability at home and in the care home, and the associated use of ATs.

Building on the vignette structures created during Stage One, the full case studies were structured into five major sections: 'Cognition', 'Family history', 'Community life', 'Relocation' and 'Care home life'. The latter three sections were ordered by chronology to indicate changes in ADL disability and AT use over time. Within the 'Community life' and 'Care home life' sections were first sub-sections relating to the person's medical and sensory conditions (co-morbidities), orientation, and mobility. Then, the focus turned to each ADL in turn: washing, grooming, dressing, elimination (toileting), and eating. The 'Community life' section had an additional sub-section entitled 'At home: informal and

formal carer assistance' to present the informal and formal human care help to each person with dementia. The 'Care home life' section had additional sub-sections entitled 'Family visits' to indicate family members' activities with the resident, and 'Care home: end of life plan' since these had been included in the vignettes. Each case study was structured identically to enable not only internal comparisons (for example, Case A's performance of washing ADL while living at home compared to her ability to wash once residing in Care home #1), but between case studies (for example, Case A's washing disability at home compared to Case B's washing disability at home). The case studies were written in the past tense when referring to the person with dementia's life when living in the community, and in the present tense to describe their current life in the care home.

The quotes contained in the interview transcripts (transcripts are not included in Appendices), case studies (see Appendix 6), and cross-case comparison analyses presented below all have particular grammatical characteristics. The quotes have no punctuation marks to prevent the transcriber (the researcher) from assuming or assigning meaning to the interviewees' discourse that may not have been intended. However, speech marks were included when the interviewee referred to what they or another person had said in the past. For example, G1 said in his interview: *'I'd say "Are you gonna do lunch for dad" and she'd say "Oh I don't think he's told me what he wants" so she'd go back again'*. Square brackets were used in four ways. First, they were used to make the meaning of the text clearer, that is, to ease the reader's understanding of the interviewee's intent. For example, H1 said: *'By the time they're at the stage that mum's at now [severe dementia] there's really no point'*. [Severe dementia] was included to give the reader awareness of the stage to which Case H was referring. Second, square brackets were used when a word was missed in a sentence. For example, C1 said: *'It was just getting too stressful [thinking] are they going to turn up'*. Third, the square brackets were used when an interviewee laughed or made a gesture, for example: *'[mimes wiping]'*. Fourth, square brackets were used when an interviewee named a person or place that needed to be kept confidential. For example, I1 said: *'When I used to go and say "Hello [Case I]" she would always be in the lounge'*. The code 'Case I' was inserted to prevent the use of the resident's real name and break the confidentiality agreement. In the quotes used to illustrate analytical points, an ellipsis, '...', between phrases indicated where words or sentences were omitted to shorten a phrase. The ellipses did not denote a silence, unfinished thought, or unfinished word.

Due to the detailed information gathered during the interviews, the 10 case studies ranged from approximately 2,700 words to 8,400 words. The reader is referred to Appendix 6 for the full ten case studies. They are not presented in the main body of this thesis due not only to word count

restrictions, but because the aim is to present the thematic analysis resulting from the cross-case comparison. First, however, some general thoughts are presented below on the benefits of collecting interview data when investigating the phenomenon of AT use in community and care home contexts.

9.3: Advantages of interview data

After the key informant interviews were conducted and case studies created, a table of each resident's pre and post institutionalisation AT use was made to comprehensively display all devices the person had used or was currently using. This information is presented below in the second and third columns of Table 10. The key informant information on community-based use of ATs was essential to explore the research questions fully, as care records did not detail technologies used by the resident when living at home. Moreover, it can be observed from Table 10 that the interview data added more devices to the list of ATs used in the care homes than had been sourced from care records, presented in Table 8 of Chapter 8. Care records were critiqued in Chapter 8 as being unable to provide a complete picture of all ATs used by, and with, a person with dementia for ADL performance (as Life History data were often absent). From interview data it was further learned that the care records did not contain complete information on even care home AT use.

The fourth column of Table 10 replicates the data in Table 8 in Chapter 8 for a clearer display of the inconsistencies in the information on ATs used in the care home collected from the care records compared to data from key informant interviews. For example, care record data indicated that Case A used only a walking stick, wet-room, call-bell, raised and winged toilet seat, instructions on managing dirty laundry, and spectacles (fourth column of Table 10). However, the key informant data showed that Case A used many more ATs in the care home, including: a mechanical bath, written instructions on how to brush her teeth, orientation labels, a mini-fridge in her room, and kettle with boil-dry protection (third column of Table 10). Thus, there were six additional ATs used by Case A in the care home that were not listed in her care record. The different number of ATs used in the care home according to full case study data compared to the vignette information is indicated in the red text in Table 10.

Table 10: Assistive Technologies used by people with dementia at home and when resident in the care home according to case study data, and compared to what was indicated only in the care record

Resident	Assistive Technologies used at home	Assistive Technologies used in the care home	Assistive Technologies used in the care home as indicated in the care record (source: Table 8)
Case A	Temporary walking frame after hip and knee replacements, telecare alarm; pendant and pull cords, hand-rails throughout flat, 'pretty' walking stick, locked safe for medication storage, spectacles	Same 'pretty' walking stick, wet-room for showering, instructions on how to shower, mechanical bath, call-bell by bed, raised and winged toilet seat, reminder instructions to brush teeth, instructions on what to do with dirty laundry, orientation labels, mini-fridge in room, kettle with boil-dry protection, spectacles	Walking stick, wet-room for showering, call-bell by bed, raised and winged toilet seat, instructions on what to do with dirty laundry, spectacles Difference: 6 ATs
Case B	Calendar, wheeled walking frame with basket, telecare alarm; pendant and pull cords, step-ladder, bath lift, jam jar opener, hearing aid, spectacles	Walking frame, wheelchair with lap-belt, stand-aid hoist with sling, nursing bed, pressure-relieving mattress, inconsistency for bed-rails with full-length bumpers, call-bell by bed, slide-sheet, dry wipes for bed baths, continence pads, commode, wet wipes for hand-washing, two-handled plastic cup with sip-top, plate guard, rubber plate bottom, fluid thickener in drinks, hearing aid, spectacles	Wheelchair with lap-belt, nursing bed, bed-rails with full-length bumpers, call-bell by bed, continence pads, commode, hearing aid Difference: 11 ATs
Case C	Walking frame, wheelchair, nursing bed, large shower installed with hand-rails, stool with hand-grips for the bathroom sink, raised toilet seat (white), continence pads, bed-sheet protection	Walking frame, wheelchair, water-chair, stand-aid hoist with handling belt, bath hoist, nursing bed, bed-rails with no bumpers, call-bell by bed, slide sheet, dry wipes for bed baths, continence pads, commode, wet wipes for hand-washing, fluid thickener in drinks, dentures	Walking frame, wheelchair, stand-aid hoist with handling belt, bath hoist, nursing bed, bed-rails – inconsistency about bumpers, call-bell by bed, slide sheet, continence pads, fluid thickener in drinks Difference: 4 ATs
Case D	Previous care activity for Case D's husband meant	Walking frame, water-chair with lap belt, stretcher,	Water-chair with lap belt, stretcher, stand-aid hoist

Resident	Assistive Technologies used at home	Assistive Technologies used in the care home	Assistive Technologies used in the care home as indicated in the care record (source: Table 8)
	that hand-rails, a downstairs bedroom and downstairs wet-room were already installed, walking frame, wheeled food trolley, telecare alarm; pendant	stand-aid hoist with small sling, nursing bed, pressure-relieving mattress, bed-rails with bumpers, call-bell by bed, slide-sheet, dry wipes for bed baths, mechanical bath, continence pads, wet wipes for hand-washing, nutritional supplement, fluid thickener in drinks, plate rim, adapted spoon, plastic cup with sip-top, spectacles, hearing aids	with small sling, nursing bed, pressure-relieving mattress, bed-rails with bumpers, call-bell by bed, slide-sheet, continence pads, nutritional supplement, fluid thickener in drinks, spectacles, hearing aids Difference: 7 ATs
Case E	Desk calendar, walking stick, telecare alarm; pull cords, hand-rail at the bath, non-slip bath bottom	Walking stick, bath hoist, nursing bed, pressure-relieving mattress, call-bell by bed, continence pads, wet wipes for hand-washing, hand-rails around toilet, shoes with Velcro fastenings, inconsistency about dentures	Walking stick, bath hoist, nursing bed, pressure-relieving mattress, call-bell by bed, continence pads, inconsistency about dentures Difference: 3 ATs
Case F	Flat already had hand-rails and raised toilet seat, calliper, walking frame, wheelchair when outside, electric scooter, bathroom changed into a wet-room	Three-wheeled walker, wheelchair, stand-aid hoist with large sling, recliner chair, nursing bed, bed-rails, pressure-relieving mattress, call-bell by bed, slide-sheet, sensor mat next to bed at night, hip-protectors, continence pads, wet wipes for hand-washing, raised toilet seat, travel-version of raised toilet seat, inconsistency about dentures	Three-wheeled walker, wheelchair, stand-aid hoist with large sling, nursing bed, inconsistency about bed-rails, pressure-relieving mattress, call-bell by bed, slide-sheet, sensor mat next to bed at night, hip-protectors, continence pads, inconsistency about dentures Difference: 4 ATs
Case G	Hand-rails, armchair elevators and commode installed for Case G's husband	Wheelchair for day trips out, nursing bed, call-bell by bed, sensor mat next to bed at night, shower seat, continence pads, long-handled shoehorn	Nursing bed, call-bell by bed, sensor mat next to bed at night, continence pads Difference: 3 ATs
Case H	The house already had hand-rails and a	Walking frame, wheelchair, stand-aid hoist with sling,	Walking frame, wheelchair, stand-aid hoist with sling,

Resident	Assistive Technologies used at home	Assistive Technologies used in the care home	Assistive Technologies used in the care home as indicated in the care record (source: Table 8)
	downstairs bathroom due to H1's injury when younger, the house also already had a bath-lift for Case H's husband	nursing bed, call-bell by bed, sensor mat next to bed at night, dry wipes for bed baths, continence pads, wet wipes for hand-washing, commode, mechanical bath, calcium supplement, fluid thickener in drinks, plate rim, spectacles	nursing bed, call-bell by bed, sensor mat next to bed at night, continence pads, commode, calcium supplement, fluid thickener in drinks, spectacles Difference: 4 ATs
Case I	Began to live on ground floor of house to care for husband, grab-rails throughout house for Case I's husband, telecare alarm; pendant, bath lift, commode	Wheelchair, stand-aid hoist with sling, nursing bed, pressure-relieving mattress, bed-rails with bumpers, call-bell by bed, slide-sheet, dry wipes for bed baths, blow-up booties to protect heels, continence pads, wet wipes for hand-washing, disposable pad for under bed-sheets, one-time catheter, nutritional supplement, fluid thickener in drinks, plastic cup with sip-top	Stand-aid hoist with sling, nursing bed, bed-rails with bumpers, call-bell by bed, slide-sheet, continence pads, one-time catheter, nutritional supplement, fluid thickener in drinks Difference: 7 ATs
Case J	'Pretty' walking stick, bath lift, non-slip bath bottom, jar opener	Walking stick, walking frame, wheelchair for day trips out, nursing bed, call-bell by bed, sensor mat next to bed at night, hip protectors, dry wipes for bed baths, continence pads, wet wipes for hand-washing, commode, nutritional supplement, fluid thickener, spectacles, magnifying glass with light	Walking stick, walking frame, nursing bed, call-bell by bed, sensor mat next to bed at night, hip protectors, continence pads, commode, spectacles Difference: 6 ATs

Table 10 shows that more ATs were used in the care home compared to community settings. The technologies in the care homes were also more sophisticated than community-based ATs, such as the stand-aid hoists, pressure-relieving mattresses with air compressors, mechanical baths, and water-chairs. A greater number of ATs used by the person once they had moved to a care home could be explained using the disablement process model (Nagi, 1965, Nagi, 1991); as the person's

dementia and co-morbidities progress over time, he or she displays more ADL disabilities, and thus there are more opportunities for AT use to alleviate these difficulties (Verbrugge and Jette, 1994). Yet, in Chapter 8, it was perceived from the Stage One vignette data that the care home environment might have favoured human over technological assistance unless safety was an issue. A detailed analysis of the data was required to fully understand AT use for ADLs in both locations.

9.4: Cross-case comparative analysis

A cross-case comparison using thematic analysis was conducted on the care record and interview data. This comparison enabled the identification of both common and unique experiences from the case studies. It also enabled carers' perceptions of ATs used by and with people with dementia to emerge more explicitly, since the case-studies were written to focus on the daily life activities of the person with dementia.

The thematic analysis process was described and justified in Chapter 7. In the first level of analysis, semantic and latent codes were applied to the data and grouped into 19 initial themes. For example, any interview discourse or care record data on institutionalisation decisions were grouped into an initial theme entitled 'Relocation or the decision about it'. Within this initial theme was information on how the decision was made, who made it, why it was made (example quote: *'They said your mum's definitely not well she's not herself I think you need to look at her going into a home'*), and the experience of relocation and the coping strategies used (example quote: *'We took stuff from her flat so it looked as much like her home as possible'*). The 19 initial themes and supporting quotes are listed in Appendix 7.

These initial themes were then subject to a second level of analysis. That is, they were split or merged as appropriate, and in accordance with this study's five research questions. This produced five potential themes with multiple sub-themes. The titles of these themes were related to this study's research questions: 'Cognitive and physical functioning'; 'Assistive Technologies used at home'; 'Perceptions of ATs and relationships with formal services'; 'The relocation decision'; and 'Care home life'. The five potential themes, sub-themes, and supporting quotes are presented in Appendix 7.

Then, the sub-themes within each of the five categories were further refined in a third level of analysis. This was to eliminate irrelevant data that did not further the exploration of the topics of

direct relevance to this research. The titles of the final themes, and corresponding sub-themes if present, are listed in Table 11 below. Again, each of the themes relates to one of this study's five research questions. Each theme and sub-theme is discussed in the following sections.

Table 11: Final themes resulting from third level of thematic analysis

Theme	Sub-themes
Theme 1: Cognitive and physical functioning at home	ADL performance at home Assistance from informal carers Lack of insight impeded the acceptance of ADL assistance
Theme 2: Assistive Technologies used at home for ADLs	
Theme 3: Managing AT use at home	People with dementia's negative perceptions prevented AT use Difficulties maintaining appropriate AT use Obtaining ATs Negotiating AT use with formal care services
Theme 4: The relocation decision	The tipping points for institutionalisation Healthcare professionals as catalysts for institutionalisation
Theme 5: Care home life	ADL performance and associated AT use in care homes Keyworkers perceived that other ATs would not be useful Family visits to the care home and ADL assistance

To note: in the description of the themes and sub-themes below, the individuals with dementia who participated are referred to using their code, e.g. 'Case A', or collectively as 'residents' or 'people with dementia', rather than 'participants'. This enables the reader to distinguish between the people with dementia at the centre of the case study, and the key informants who were interviewed participants in Stage Two. All quotes are prefixed by the code of the speaker; 'I' means Interviewer (the researcher). Finally, it is reiterated that the themes below detail the life of each person with dementia, yet all data were sourced from the retrospective accounts and perspectives of key informants and from care records which were completed by formal carers.

9.5: Theme 1: Cognitive and physical functioning at home

The first theme, entitled 'Cognitive and physical functioning at home', relates to research question 1: what cognitive and physical difficulties did people with dementia have performing ADLs when they resided in the community? The theme has three sub-themes. In the first sub-theme, cognitive and physical functional limitations resulting from dementia and co-morbidities which were thought to impact on general and specific ADL performance are presented. Some indication of the housing environments of those with dementia is also given. In the second sub-theme, the human assistance given by family members to their relative with dementia is discussed. In the third sub-theme, the

discussion returns to a common difficulty resulting from cognitive impairments associated with dementia: lack of insight into their own disabilities, which impeded the extent to which people with dementia were amenable to ADL assistance. The findings help to fill the gap in knowledge observed in Chapter 3 concerning the specifics of how ADL difficulties are experienced by people with dementia.

9.5.1: Performance of ADLs at home

In this sub-theme, first some details of cognitive difficulties that were perceived to impact upon ADL performance are discussed. Examples are given to illustrate the influence of memory impairments, visuo-perceptual mistakes, and disorientation to time and possessions on ADLs. Then, what was reported about the physical difficulties perceived to result from the dementia is considered. The physical issues associated with reported co-morbidities are also included in this discussion. Then, the housing environments within which those with dementia lived in the community are briefly given. Finally, the ADL disabilities people with dementia had while living at home are presented. First, difficulties with washing and bathing are discussed, then grooming and dressing activities, then toileting and continence, and finally feeding and eating.

Cognitive difficulties

Informal carers reported a wide variety of cognitive impairments displayed by their relatives with dementia when they lived at home. These included: impaired short-term memory; hallucinations and delusions; disorientation; mood changes; language problems; inability to concentrate; poor sequencing of actions; and difficulty making decisions. These factors were all perceived to impact on the performance of ADLs. Examples from the interviews relating to memory, hallucinations and delusions, and disorientation now follow. Memory impairments were perceived by family members to impact on the person with dementia's ability to remember to perform whole activities, tasks, or actions:

G1: She was obviously forgetting things we got worried about [her] personal hygiene

Thus, the need to perform crucial ADLs was often forgotten. Visuo-perceptual mistakes caused hallucinations, and reduced awareness of surroundings often manifested as delusions. These blurred reality for people with dementia. For example, some had been known to soil themselves because they thought there was already someone in the bathroom, having merely seen their reflection in a mirror. Therefore, toileting and continence were affected. Disorientation was frequently-reported to

impact ADL performance. For example, disorientation to time meant people with dementia would think that it was time for bed in the middle of the afternoon:

E1: She'd say "I'll go to bed now" and you'd say "No it's three o'clock in the afternoon" "It's three o'clock in the morning I should be asleep"

Disorientation concerning place or location of possessions was also common. For instance, Case A would not get dressed because she did not believe her clothes were hers. While disorientation affected daily life, for some activities this was not a critical issue. However, if disorientation meant that an individual missed meals or hygiene activities, ADL assistance would be needed to prevent a crisis relating to safety and well-being.

Once these cognitive symptoms and resulting behaviours were displayed, people with dementia were no longer seen by others as able to manage their own ADLs without assistance. However, it was difficult to determine from the narrative accounts whether, or how, particular cognitive symptoms influenced specific actions, tasks, or activities. Rather, cognitive impairments were seen to combine to affect ADL performance.

Physical difficulties

While not every person with dementia had difficulty performing all of the ADLs while at home, they all experienced mobility difficulties. Immobility is considered a functional limitation in the disablement process model (Nagi, 1965, Nagi, 1991, Verbrugge and Jette, 1994), and thus leads to ADL disability. Informal carers perceived that mobility was affected because of physical impairments of joint weakness, muscle weakness, and reduced balance. Often, informal carers attributed these physical impairments and functional limitation to dementia:

C1: The main thing was that he lost the use of his legs... he had tests to see if it was circulation to see if it was loss of muscle no it was simply the brain didn't tell his legs to move

Case B also fell frequently despite no discernible physical issues, that is, no diagnosed co-morbidities. Indeed, falls were common among people with dementia. They all experienced a fall with some kind of acute injury: broken bones, joint dislocations, and lacerations. After falls, they were then usually seen by families and health professionals as requiring care. Although these individuals did not, while living at home, have 'the dementia shuffle' (as H1 called the unsteady gait

she observed was common among people with severe dementia) they were perceived as becoming frailer. Reduced mobility caused difficulties moving around the house and thus impacted on ADL performance; for example, navigating steps and stairs to the toilet, and getting into the bath. However, the clinical explanation for why dementia affects motor skills and other physical functioning actions is not the focus of this thesis.

Co-morbidities were also reported by family carers as affecting physical functioning. Nearly all of the people with dementia were diagnosed with at least one health condition relating to their heart or vascular system. The most common were strokes or TIAs (transient ischaemic attacks - also known as mini-strokes). Many also had hypertension, Deep Vein Thrombosis (DVT) and hypercholesterolemia. Some had a history of lung conditions such as pneumonia and recurring chest infections, leading to breathlessness on exertion. Musculoskeletal conditions were also commonly reported, particularly osteoporosis, osteoarthritis, rheumatoid arthritis, and gout. Skin conditions, such as cellulitis and oedema, were experienced by some. As the disablement process model indicates (Nagi, 1965, Nagi, 1991, Verbrugge and Jette, 1994), these co-morbidities lead to physical impairments of pain, breathlessness, stiffness, and weakness. These impairments then lead to functional limitations such as immobility, which in turn contributed to ADL disability. For example, arthritis (pathology) caused pain in Case A's shoulder (impairment), reduced her ability to move it (functional limitation), and meant that she needed assistance to put on her bra (dressing disability).

Co-morbidities were reported to not only affect a person's mobility. For example, following a stroke Case A was no longer able to feel and therefore perceive the left side of her body:

A1: She would always whack her left shoulder on the door because she just wasn't aware it was there... all the shirts she was ironing it dawned on me that they were perfect on the right hand side but the left hand side she hadn't seen them so she didn't iron that side at all

After this impairment was identified, her family increased the help she received. From then on, food in Case A's refrigerator was placed on the right hand side, or she would not see or eat it.

The pain they experienced due to co-morbidities was particularly dangerous for people with dementia, since their cognitive impairment meant they could no longer store short-term memories. For example, Case A could not remember when or if she had already taken painkillers, so twice accidentally overdosed on pain medication. Her daughter, A1, then felt obliged to lock her pills away,

upsetting Case A. This harmed their relationship, but it was felt necessary by A1 to manage Case A's safety. Indeed, both examples above concerning Case A indicate that physical safety, such as preventing injury or malnutrition, was a particular concern for informal carers and was the main initiator of their assistance.

The most commonly reported psychological co-morbidity was depression. Linked behaviours included: crying, anger, and apathy. One person with dementia took medication for anxiety. Psychological illnesses such as these may impact on ADL performance, for example by reducing appetite and therefore affecting eating ADL, or the motivation to wash oneself.

Housing environment

Given that ADL disability occurs in unsupportive environments (Nagi, 1965, Nagi, 1991, Verbrugge and Jette, 1994), informal carers were asked about their relative with dementia's homes. They were not asked to describe each room, but rather to indicate how supportive the environment was in meeting their relative's cognitive and physical functional limitations. Overall, there was an almost even split between those people with dementia who stayed in their own multi-storey family houses until institutionalisation, and people with dementia who moved to a more suitable community-based environment better able to manage their cognitive and physical needs. Those who moved tended to relocate to flats of semi-sheltered status with a human warden or telecare alarms. Some of these flats had hand-rails and other environmental modifications as standard. Although ground-floor flats were perceived to be more effective at addressing mobility difficulties, some people with dementia preferred first-floor flats as they felt safer. Case C was an exception, as he and his wife moved into a bungalow post dementia diagnosis. However, this new environment could not support his needs for long: C1 had to install environmental modifications as Case C's immobility progressed. These included a ramp from the house to the back garden and bathroom modifications.

The other half of those with dementia stayed in their family homes. Their housing environments were also often adapted. For example, a downstairs shower room was added to Case D's house; without this D1 perceived that Case D would have had to relocate to a care home sooner than she did. Those who did not adapt their homes struggled to manage. For instance, Case G and her husband continued to live in their un-adapted family house, even though his immobility meant he had to crawl up the stairs to the bathroom. Informal carers' reports of impaired performance of the ADLs under investigation will now be discussed, beginning with washing and bathing. The reported ATs used for these ADLs follow in Theme 2, section 9.6.

Washing and bathing

Both cognitive and physical impairments impaired the performance of washing and bathing among people with dementia. Memory impairments were especially salient. As indicated earlier, over time people with dementia would completely forget to take care of their washing and bathing needs. They also forgot how to use bathroom fixtures appropriately. For example, Case A frequently forgot she had left taps running and flooded her bathroom. Others could no longer remember how to turn on the shower. Sequencing difficulties meant that people with dementia could not understand the appropriate order of the individual tasks that made up the ADL. For example, as Case C's dementia progressed he could no longer remember how to use soap and shampoo. Physically, the people with dementia had impairments typically because they could not get in and out of the bath without difficulty. Case D refused to bathe on her own because she was afraid that she would fall or get stuck. Informal carers felt that showers were easier, physically, for their relative as long as they could remember how to operate them. Thus, cognitive and physical functional limitations combined to influence ADL performance. Of course, the environment had an impact: it is possible that simple shower fittings and low bath sides could have prevented some washing and bathing disability.

Grooming and dressing

Grooming activity was rarely notably impaired while the people with dementia still lived at home. For instance, most people with dementia could brush their teeth and remember the steps to complete this activity. Only Case H required verbal prompting for this activity while living in the community. Case C eventually required shaving by formal carers. This was due to poor physical functioning of the wrists and hands, and his inability to remember the sequence of required actions.

Difficulty dressing was often displayed, and perceived to be impaired due to both cognitive and physical functions. Cognition affected dressing in six distinct ways. First, disorientation to the correct weather and season of the year meant that some had difficulty understanding the appropriate clothes to wear. For example, Case A wore cropped trousers and a sleeveless top in winter because she had been reading an old summer edition of a magazine that recommended it. Second, many people with dementia could not make decisions with respect to selecting clothing for the day given diminished decision-making capacity; informal carers would then put out clothes for their relative to wear. Third, some people with dementia forgot how to put items of clothing on appropriately:

I1: She couldn't work out how to get her body parts into the right bits of the clothes... she couldn't put a blouse on she would get in a muddle doing quite simple things like that

This difficulty was perceived to be a combination of memory impairment, poor sequencing, and impaired logic when faced with items of clothing. Fourth, disorientation to possessions meant that some people did not recognise that the clothes were theirs, and so refused to wear them. This happened to Case A at home, because she believed her flat was not hers and thus neither were the contents. Fifth, eventually some people with dementia had difficulties in remembering or perceiving that they needed to dress at all, and so required reminding to do this. Sixth, it was reported that people with dementia had difficulty realising that clothes were dirty and required washing:

E1: Sometimes I'd say "Oh you need to put a clean skirt on tomorrow" so I'd put a clean one out and think she'd put that on tomorrow and then you'd go back and find she'd just folded it up and put it back in the wardrobe and put the same one back on

This was mainly due to the person's inability to remember they had recently worn the item. However, the latter three problems presented here were more commonly displayed by people in the moderate to severe stage of dementia and thus only experienced once in the care home.

Toileting and continence

Only Case C, the one male with dementia in this study, was incontinent while living at home. Generally, incontinence was rare for the people with dementia when they lived in the community. There were some occasional 'accidents'; causes were attributed by families either to drowsiness from medication or some aspect of cognitive impairment. Case I's toileting difficulties were perceived by her niece-in-law to be largely related to sequencing actions and understanding how to wipe herself, rather than incontinence from a lack of control over her sphincter muscles:

I1: Going into the bathroom one morning there was faeces absolutely everywhere so certainly in terms of continence she hadn't lost control of her bladder or bowels at that time but it was more managing her care when she went into the bathroom wiping herself and cleaning herself up... I think that was probably a spatial thing... definitely related to the cognitive issues

Yet, Case F's occasional incontinence was because she could not mobilise to the toilet in time, and not because she had not perceived her need evacuate her bladder. Thus, physical functional limitations were also the cause of toileting disability. Incontinence as a result of not understanding the need to eliminate was not displayed by people with dementia until their dementia progressed, and they were residing in their care home.

Feeding and eating

Difficulties with feeding and eating when at home largely concerned impaired performance of the IADL of preparing food. This was linked to people with dementia's inability to remember how to put a meal together, and how to sequence the appropriate actions. Case E never touched any food in her freezer. E1 believed this was because Case E either forgot that the freezer existed, or how to heat up the food contained within. Generally forgetting about eating was also displayed by Case I, who received meals-on-wheels but still forgot that the food was ready for her in the kitchen.

The consequences of memory loss on feeding and eating ADL were severe. For example, Case A began to suffer frequent UTIs because she did not remember to drink enough fluid. Case E unwittingly abused alcohol, as she forgot that she had already had her nightly tot of whisky. Case G, who was living with her husband who also had dementia, forgot to give him food and he was subsequently diagnosed with malnutrition:

G1: She'd say "Do you want egg and chips?" and [husband would] say "Yes ok" and then she'd come out and I'd be in the kitchen doing something and I'd say "Are you gonna do lunch for dad?" and she'd say "Oh I don't think he's told me what he wants" so she'd go back again and this would go on so I'm thinking when I'm not there she's probably not getting him anything

Disorientation to time of day also impeded people with dementia's ability to understand mealtimes. Some also claimed to never feel hungry; this may have been because their brain was no longer able to pick up satiety signals from the stomach. More noticeable to informal carers was that their relatives' tastes changed as their dementia progressed. For example, Case E would say in the supermarket that she wanted peach yoghurt having remembered that she always ate it, but upon tasting it at home would refuse to eat more. Many family members reported an increased preference for sweeter foods; this meant main meals were sometimes refused. However, people with dementia could physically perform feeding actions, and could co-ordinate cutlery once food

was in front of them while they lived at home. They received some gentle verbal prompting to eat from family members, but no physical feeding assistance was given. This was the only one of the ADLs whereby cognitive impairments were more salient than physical impairments.

9.5.2: Assistance from informal carers

This sub-theme relates to the assistance that informal carers gave to their relatives with daily activities. However, informal carers' assistance to relatives with dementia was largely related to IADLs rather than ADLs. Formal care services were contacted once a need for help with ADLs was perceived. The IADLs that families assisted with were often related to finance management, shopping, and housework. Examples for the latter two follow. Some family members took over shopping IADL for their relative completely, and shopped for them online or alone. Others would accompany their relative to the supermarket and assist them with decisions. Some informal carers reported checking their relative's cupboards to see if their shopping list was appropriate:

I: Did you have to check round the house and make sure the list was accurate first?

B1: I didn't really get round to doing that I probably shoulda done towards the end because you'd find she'd got a three week supply of tomatoes and cereal

Informal carers also helped with housework. This was not only because of their relative's increasing physical frailty, but also because cognitive impairment reduced the persons' ability to perceive housework needed doing:

E1: If you said "Let's Hoover the floor" she'd say "It doesn't need hoovering I don't make a mess"

Thus, the dementia often impeded the person's ability to feel that a task needed to be done. They also displayed no acknowledgement that they had disability with IADLs and ADLs and that they required some type of assistance with them. This is discussed in more detail below.

9.5.3: Lack of insight impeded the acceptance of ADL assistance

Only E1 and her sister directly performed physical ADL assistance to a relative with dementia in the community. They helped Case E to bathe, and creamed her skin once a fortnight. Informal carers may have reported providing less ADL assistance than expected because their relatives with

dementia often displayed a complete lack of insight into their own disability. That is, owing to their inability to create new memories, people with dementia would think that they could perform activities as they always had done throughout their life. They would be unable to perceive or remember that they had difficulties in ADL performance. Typically, they would deny they had anything wrong with them and disagree that they required human or technological assistance, although Case I may have been aware that something was not quite right:

I1: We sorted a lot of the chaos out [in Case I's house] and there were thousands of notes she was writing absolutely everything down hundreds and hundreds and hundreds of bits of paper with every possible thing

Lack of insight, coupled with diminished social skills and inhibitions, meant that people with dementia became vocally aggressive if they did not want the help given to them. To manage their relative's resistance, many informal carers realised that they had to carefully choose their language to persuade them to accept help and to reassure them:

J1: "But I'm independent I'm self-sufficient" so you had to word it properly

J2: Once she'd decided she didn't want [bath lift] and didn't want to use it you were not going to convince her to use it so the solution was to say "Well fine don't use the bath so much use the shower so we'll sort out the shower footing [to make the shower floor non-slip] for you instead"

Continuing to try to persuade Case J to use her bath lift only led to arguments with her daughters. Thus, Case J no longer used her bath lift. This illustrates that not only did lack of insight impede a person with dementia's ability to accept human assistance, but also technological assistance. Theme 2 below explores the extent to which ATs were used for ADLs.

9.6: Theme 2: Assistive Technologies used at home for ADLs

The second theme, entitled 'Assistive Technologies used at home for ADLs', relates to research question 2: what types of ATs did people with dementia and their informal and formal carers use to assist their performance of ADLs while living at home? Although this research focuses on devices for ADLs, these were very rarely used at home. Informal carer interviewees therefore discussed any

technologies their family member employed to assist in daily life. First, ATs used for disorientation and mobility are presented, as nearly all AT use was related to immobility and physical frailty. This is followed by the ATs used for the ADLs under investigation. Overall, most ATs for ADL performance were designed to support physical rather than cognitive functional limitations. No dementia-specific ATs were used for ADLs. The findings help to address the gap in knowledge observed in Chapter 4 concerning the actual ATs used by people with dementia for the ADL difficulties.

Disorientation

No dementia-specific orientation technologies were used at home, such as: room or item signs, talking clocks, or memo minders. Some people with dementia used calendars to help plan their time and to orient them to the date. For example, Case E would telephone her daughter every morning to ask her the day and time. E1 would then encourage her to look at her calendar and plan for the day:

E1: She'd go "My calendar says... nine-thirty [time of the morning] bus ride for [day centre]"

G1, however, was not confident that Case G looked unprompted at the calendar notes he made:

G1: She'd always had a calendar so it was something that she was familiar with... I set up a notepad for her to write [a] shopping list and key things that are going to happen and the carer's name and things but I'm not sure she really looked at that

However, calendars were not used by informal carers to remind the person with dementia to perform ADLs. Merely, they were used for general daily life and planning social events.

Mobility

Assistive Technologies for immobility were widely used. Nearly all people with dementia had some technological assistance with walking as a result of pain, frailty, or poor balance. Some of these ATs were active devices that required the user to operate them, such as a walking stick. Sticks and wheeled walking frames were usually necessary, although Case E was unique as she used a stick only to give her confidence when walking. As had been observed from care record data in Chapter 8, people with dementia used more sophisticated ATs over time and as their functional limitations increased. The best example to illustrate this is Case F. She started using a calliper on one leg to aid her muscle stiffness. Over time, she had a walking frame, which she understood how to use because her husband had used one before he died. As she became frailer, it became necessary for her to

have a wheelchair when outdoors. However, her housing environment meant that she did not use the wheelchair indoors, as she could hold on to grab-rails and furniture to mobilise. Case D's family encouraged her to push a wheeled hostess trolley when indoors so that she did not have to carry a cup of tea in her hand when walking. However, she did not usually use this:

D1: I think she just forgot really she just sort of would get up with her teacup in her hand and she would walk she'd just forget that she was meant to put it on there and then push it

Case D forgot the trolley was there for her use, owing to memory impairment. Indeed, others could not remember how to use ATs. Case I, who was very frail, had a stair-lift in her house which had been previously installed for her late husband. However, she could not use it because of her cognitive impairment:

I1: Partly because she didn't remember that she could use it herself her perception was that it was there for [husband] and however many times you would tell her she couldn't learn to use it

Case C had a nursing bed on loan from the local authority adult social care services. This enabled him to sit up in bed, to ease dressing and bed bathing. This was the technology that C1 felt was the most helpful to Case C. However, this large item necessitated Case C use the parlour as his bedroom, thus separating him from his wife. C1 did not report whether Case C could operate the rising mechanism or whether others activated it for him. Overall, many active devices for mobility were unusable owing to the person's cognitive impairment: they could not remember how to use them. Some had devices that were passive and modified the environment, such as hand-rails. These were reported as useful by the informal carers.

Washing and bathing

Community-based devices related to washing and bathing all supported physical functional limitations rather than affecting people with dementia's cognitive ability in relation to understanding how to wash. Dementia-specific washing and bathing technology such as temperature alarms, flood monitors, and tap modifiers were not used at home; informal carers were not aware that these existed and they had not been offered by formal care service staff. The only reported devices requiring active use were the bath lifts regularly used by Case B and Case H. However, Case J could not use her bath lift as she was unconfident about its fit in her bath. Thus, her environment (the

bath) impeded the potential use of an AT and continued to contribute to disability. Case J was also reluctant to bathe as she preferred showering. Her daughters then bought a non-slip mat for the bottom of the bath to prevent slips and falls. This AT manipulated the same environment (the bath) to reduce disability and prevent a potential acute incident. Indeed, passive environmental modifications or devices were more commonly reported than active ATs. The houses of Case A, Case E and Case F had grab-rails already installed near baths and sinks as standard. C1, who as Case C's wife was the only informal carer who lived with their relative with dementia, remodelled their bathroom to aid her husband's immobility. Her environmental modification included a wide shower with seat and handgrips, and a stool for him to sit at when at the washbasin.

Grooming and dressing

Although some dressing disability was experienced, as discussed in sub-section 9.5.1 above, ATs for grooming or dressing ADLs were not used at home. Informal carers did not indicate that their relatives had manipulated their environment to manage this; that is, they had not changed the types of clothes they were wearing to have easier fastenings. They did not use grooming and dressing ATs such as elasticated shoelaces or long-handled hair brushes. Rather, grooming and dressing needs continued to be managed by the person with dementia themselves, or with assistance from carers.

Toileting and continence

Similar to the washing and bathing ADL, ATs and environmental modifications used for toileting and continence largely supported immobility, and particularly the person's ability to get on and off the toilet. Handgrips or toilet frames were used by Case A, Case C, Case F, and Case H. Case H's home already had a downstairs bathroom with hand-rails because of H1's childhood accident. Case C and Case F also used raised toilet seats. These were white and therefore not dementia-specific in design, given that coloured contrasts may have aided their identification against surroundings. Nevertheless, F1 felt that the raised toilet seat was helpful, for a time:

F1: We [F1 and wife] could get her onto the toilet no problem particularly with the raised seat which was very minor it's an amazing thing so that worked well for a while

Case I had a downstairs commode to prevent her from navigating the stairs. However, she did not use it as she forgot it was there. Thus, although ATs to manage physical functional limitations were present, the additional cognitive difficulties often impeded device use. Concerning incontinence,

Case C was the only person with dementia to be regularly incontinent while living at home, and the only one to use continence pads. His wife privately purchased him pull-up style continence pads.

Eating and feeding

At home, no technologies for feeding such as plate rims, thick or angled cutlery, or adapted mugs were needed or used. However, some devices were purchased by informal carers to assist the IADL of preparing food. E1 bought Case E a potato peeler with a thicker handle:

E1: But I don't know how much she used it because she tended to like to use the things that she'd always had

Case J also had a gadget to make opening jars easier. However, she also would rarely use it because she could not remember its function. Similarly, Case G was bought a microwave by G1. She again could not remember how to operate it, even though he had taught her how to use it many times. Thus, the introduction of new or different devices for preparing food was not helpful for people with dementia, owing to their inability to learn and to hold short-term memories. These and other barriers are discussed in the following theme.

9.7: Theme 3: Managing AT use at home

The third theme, entitled 'Managing AT use at home', relates to research question 3: what were informal carers' preferences, barriers, and facilitators with respect to the use of such ATs by people with dementia when they lived at home? There are four sub-themes within this theme. In the first sub-theme, the negative perceptions that people with dementia had towards potential AT use are discussed. Three further issues people with dementia had when trying to maintain their use of an AT once it was in their lives are presented in the second sub-theme. The third sub-theme concerns from where ATs were obtained by people with dementia and their informal carers. In the fourth sub-theme, the role of formal social care services when negotiating AT use is explored. This particularly concerns: the role of health and social care professionals who managed to change the person with dementia's mind about receiving human and technological ADL assistance; how families had to push for the devices they wanted; and informal carers' continued suspicions of the quality of care given by formal carers even with the use of sophisticated ATs. The findings help to fill the knowledge gaps presented in Chapter 4 concerning the use of ATs by people with dementia for ADL difficulties.

9.7.1: People with dementia's negative perceptions prevented AT use

Generally, informal carers expressed appreciation for mobility-related technologies, continence pads, and calendars that were used, as they made daily lives easier. Informal carers were open to the potential use of ATs for ADLs in principle. However, when discussing their retrospective experiences, they reported more negative than positive encounters of device use at home. Overwhelmingly, the barriers family members faced with respect to ATs were not related to their own perceptions of technologies for ADLs, but to the negative perceptions of their relatives with dementia. These negative perceptions are presented below.

The most pertinent issue preventing potential use of new ATs was the person with dementia's resistance to any kind of technological assistance because they felt it was not needed. People with dementia liked circumstances to remain the same, and so resisted any kind of change. Coupled with their lack of insight into their ADL disability, as discussed in sub-section 9.5.3, many emphatically denied they needed help:

J1: I suppose in some respects we were very tentative with giving her Assistive Technology because she would see it as a crutch and God forbid she needed a crutch... "But I'm independent I'm self-sufficient"

Another issue was that people with dementia felt they would be viewed negatively by other people as old and frail if they used ATs. Again, informal carers learned to use persuasive language to encourage AT use. Case J's daughters managed to persuade their mother to use a walking stick by discussing how her use of it would more positively change other people's perceptions of her:

J1: [She] didn't want to be seen accepting help and I said to her "You need to use the walking stick for the likes of me who are walking down the street quite quickly who will get annoyed you're not moving but if I saw a walking stick I give you a wider berth it gives me a heads up this person's unsteady on her feet they're not gonna go very fast" I said "It's not about you mum" so of course she thought "Ok then I'll use my walking stick"

It was also reported that people with dementia felt that the presence of ATs was 'too much fuss' for their lives. Case J refused to receive or talk about ATs because she perceived this as her family becoming over-involved in her life:

J1: *There's only so much you could do because then she say it was too much fuss*

J2: *"Don't want to do it don't care about it don't talk to me about it"*

Her daughters were then reluctant to provide Case J with ATs, as it made her angry.

9.7.2: Difficulties maintaining appropriate AT use

There were also issues related to the maintenance of AT use; that is, continued appropriate use, even once a person with dementia accepted a device in their life. Owing to short-term memory impairment, often people with dementia could not remember a device was even present in the house and available for their use. For example:

I1: *It would have been very difficult to get her to use [a downstairs bathroom] because she would automatically come out of the lounge and go upstairs because that's where the bathroom was it wouldn't even have been on her radar that there was another bathroom*

It was also often reported that impairment in short-term memory, reasoning, and logic impeded the person's ability to learn how to use an AT and retain that information for future use. For example, G1 bought Case G a new microwave to prevent her from using the oven because he worried that she would cause a house fire. Although she had used microwaves in the past, Case G was not able to use the new device no matter how many times G1 taught her. She also struggled to use a medication box that had separate compartments for each day, as she could not remember how to open it. This inability to learn, because the information could not be retained, was important in shaping informal carer's perceptions of the role ATs could have in daily dementia care. This was when family members began to show more negative attitudes toward the use of ATs:

H1: *When you've got dementia there's so many variables the idea of having this help is great if they are able to use it and if they're in the mood to use it... by the time they're at the stage that mum's at now [severe dementia] there's really no point it's more hands-on need people to be around her*

Given that people with dementia struggled to learn to use new devices, there was some indication from informal carers that ATs designed to look like technologies that the person might have used in the past may have been more appropriate. Certainly, the people with dementia expressed a

preference to use older devices that they already owned. For example, Case E's short-term memory impairment meant that she would not use her new tin-opener with a large handle because she only recognised her old tin-opener as belonging to her. E1 reported that Case E was also wary of new technology that looked too dissimilar to traditional objects. For example, when discussing the possible use of large-handled and brightly-coloured cutlery:

E1: Whether [she] would identify something that was a completely different colour as being a piece of cutlery... because all her life cutlery has been silver

E1 further explained that her mother now lives 'in the past'. That is, she believes that she is younger than she is and responds well to reminiscence-type activities. This may mean that people with dementia may react more positively to ATs with historical designs than to modern-style devices.

Another issue was that of appropriate use of technologies. Informal carers reported that their relatives would misuse some ATs, particularly those used for safety and communication reasons such as telecare pendants, pull-cord alarms, and large-button telephones. Informal carers reported that these devices were subject to misuse by the person with dementia through either under or over-use. For example, Case A, Case G, and Case I under-used their alarms because they: did not want to be a nuisance to others; did not perceive that they needed them; could not remember that the alarms were there; and could not remember how to use them. In contrast, Case B and Case E over-used their alarms and became a nuisance to the alarm call centre. B1 felt this was because Case B forgot that she had recently used the cord and spoken to the staff members at the call centre. However, E1 perceived Case E's overuse appeared to be related to having someone to talk to and feeling lonely. Indeed, Case E would overuse her pull-cords, but refuse to wear a pendant or watch alarm. Similarly, Case G used her large-button telephone to call G1 repeatedly not only for reminders and to be reoriented to the day's events, but also because she wanted more human interaction.

9.7.3: Obtaining ATs

Technologies used by people with dementia at home were obtained from three main sources: an item was already owned within the family or social network because of a previous need; informal carers purchased the device from a mobility shop; or the AT was provided by formal services.

Some ATs were used because an item was already owned by the person with dementia, their family, or a social connection. For instance, Case J's bath lift was purchased by her daughters from a friend,

although they had to employ a fitter to install it. Mobility-related technologies in particular were often sourced from the person with dementia's family. For example, both Case E and Case F used walking ATs that had been previously used by their husbands. However, these devices sometimes required adaptation. For example, Case E's falls clinic modified her husband's walking stick to fit her body. Pertinently, knowing her walking stick was unique helped encourage Case E to use it:

E1: She didn't like using the one the hospital gave her because it was just... like everybody else's whereas the one she had was different

Similarly, Case A and Case J preferred their 'pretty' (usually floral-patterned) sticks which, they perceived, helped to prevent other people from thinking they were 'old'.

Most devices that were used were obtained from private sources; usually AT magazines or mobility shops. For example, Case B bought her bath lift and kitchen aid for unscrewing jars from an AT catalogue she had. However, A1 had problems with AT magazines, as Case A would order items she did not need or were not safe for her to use:

A1: She'd be on the phone ordering all these... mobility scooters and this scooter and that scooter because she used to drive but we took the key off her

Thus, although Case A perceived the need for some mobility-related ATs, her impaired logic and reasoning meant that she tried to order inappropriate items. Family members commonly sought aids from mobility shops, especially those who did not have the internet. Although initially informal carers thought that only mobility-related technologies could be purchased in such places, they had been surprised by the other types of ATs for sale:

F1: [It opened] a whole new world to me I didn't realise how much is available

For example, G1 bought rubber sheets and pillow covers for incontinence from a mobility shop for his father, Case G's husband. G1 also purchased emergency continence pads from the mobility shop when the stock of those received from continence services had temporarily depleted.

Continence pads were provided free by healthcare services. Of the ATs that were obtained from Local Authority (LA) adult social care services, only some needed to be paid for. For example, Case B

paid in instalments for her telecare alarm from her LA. However, Case C's LA loaned him a nursing bed and bathroom technology for free. Once he relocated to Care home #2, C1 returned the sink stool but was told to retain the raised toilet seat. Given such little use of different ATs by the people with dementia in this study, and their residence in multiple LAs, why some ATs were funded and others were not could not be determined using these data. This was also not the focus of this study. Informal carers indicated that social workers, OTs, and 'hospital almoners' (C1 used this term for the person who had assessed her house) were typically the main professionals to 'prescribe' an AT:

D1: The rails were put in on the basis of the Occupational Therapist's recommendations

Thus, the presence of ATs sourced from formal social care services were more commonly due to the recommendation of a care professional, rather than because an informal carer had perceived the need for a device and contacted their LA. However, some issues impeded relationships between the caring dyad and formal care services. These are discussed below.

9.7.4: Negotiating AT use with formal care services

There were four findings regarding the negotiations between people with dementia, families, and formal care services for human and technological ADL assistance. First, people with dementia could often only be persuaded to use formal care services and ATs when in the presence of a health or social care professional that 'prescribed' it to them or encouraged them to use it. Second, family members felt that they had to 'push' formal services for the human care and ATs they needed, which delayed or discouraged use of appropriate technologies. Third, communication between people with dementia and formal carers was often difficult owing to cognitive impairment and many carers' foreign accents. Fourth, even when the person with dementia was in receipt of formal human carers who also used ATs, family members remained uncertain about the quality of care given.

The first finding links to the issues discussed previously concerning people with dementia's lack of insight into their ADL disability, and thus refusal to accept help. Informal carers reported that their relatives with dementia were less resistant to the receipt of formal care services (humans or ATs) if they had been told to use them by a health professional, compared to the same suggestion from a family member. For example, Case E only agreed to trial a day centre when the District Nurse encouraged and accompanied her. Case G only accepted formal carers for her husband, and eventually herself, when it was made clear to her by doctors that if she refused then her husband would have to be institutionalised. She was taught to perceive formal care as an extension of her

husband's treatment rather than as a social care situation for herself. Concerning ADLs and the influence of healthcare professionals, Case J refused to eat until a doctor explained that she needed to fuel her body. This extended to the use of ATs. For instance, E1 reported that she felt that Case E only used a walking stick because her GP had told her to. E1 felt that if she had suggested a walking stick then her mother would have refused to use it. Informal carers perceived that the suggestion of AT usually needed to come from health and social care professionals. This was thought to be because the people with dementia had been taught to respect the opinions of professionals when growing up, and so felt unable to argue with them as they could with their daughters and sons.

Many family members felt that they had to be persistent in their communication to obtain relevant information on what human and technological support was available. The word 'push' was very common in interviewees' rhetoric whether trying to gain financial, human, or technological aid:

D1: And [the council] said "We will give her some [funding] within reason give us an application" so we did we pushed at lots of people it wasn't easy I have to say

C1: [District Nurse] said "Oh no we can't provide [pull-up continence pads]" "Why not" she said "Well it's cost I'll send some others" well she sent me various variations of [stick-in continence pads] all of which were useless... because I'm very persistent I think [laughs] I eventually got them

G1 had to push to obtain meals-on-wheels for Case G. Her husband was already receiving this service, but she was ineligible. She only received meals-on-wheels after G1, in his words, 'got stropky'. Yet, others did not have to push if they had a health visitor or social worker that became trusted long-term contacts. These individuals were useful sources of information on what could help people with dementia and their families:

D1: I remember spending lots of time trying to work things out mind you the health visitor was quite good as well... she said "Why don't you try and do this or try and do that"

The individuals above obtained help because they wanted it and pushed for it. Conversely, Case H's husband, who cared for her before he died, was actively against receiving help from formal services. He thought that if he informed social services Case H had dementia then she would be 'taken away

from him', as was common many years ago. Tragically, H1 perceived that if Case H and her husband had received formal care at home, then her father would have lived for longer.

Yet, for those people with dementia who received formal human and technological assistance for ADLs, there were still issues. It was commonly reported that communication was difficult between the person with dementia and formal carers. One reason was because of the language difficulties caused by dementia, such as: needing more time to process a sentence they heard; struggling to formulate responses; or finding appropriate words. Then, holding a conversation with formal carers and understanding what they were doing was difficult for people with dementia. This resulted in resistance, particularly during personal hygiene activities such as washing. A second problem was that many of the health and social care professionals and formal carers were not native English speakers. Foreign accents became much harder for people with dementia to interpret, which resulted in anger or mistrust of the professional or formal carer.

Another issue was that even when formal carers used ATs with the people with dementia, such as bath lifts and stand-aid hoists, the use of such technologies could not alleviate informal carers' perceptions of poor quality care. For example, although C1 was happy with the ATs loaned by her local council, her problems with at-home care were because of poor time-keeping. When Case C's mobility declined further, and the carers suggested they use a stand-aid transferring hoist, C1 decided that this would not work because there would need to be two carers at a time to operate it with him. She felt, based on previous experience, that she could not trust two carers to arrive at her house at the same time:

C1: It wasn't the problem with the hoist although it may have been a problem with some ceilings... it was the problem with the carers not coming on time... they didn't turn up at the same time sometimes they didn't turn up at all... it was just getting too stressful [thinking] are they going to turn up does [Case C] need changing how can he get to the loo

As such, Case C's increased immobility, and C1's reluctance to allow the stand-aid hoist into the bungalow, became the tipping point for his institutionalisation.

9.8: Theme 4: The relocation decision

The fourth theme, entitled 'The relocation decision', relates to research question 4: what was the tipping point for the person with dementia to relocate to a care home and was this decision at all related to ADLs and AT use? This theme has two sub-themes. The first sub-theme relates to the tipping point for institutionalisation. Often, a combination of cognitive and physical functional limitations led to the tipping point. The presence and use of suitable ATs were not perceived by informal carers to have delayed the decision. The second sub-theme concerns the relocation decision: the advice of a health professional was often the key catalyst. The health professional's involvement was usually a result of an acute event experienced by the person with dementia, such as a fall and hospital stay. The professional's recommendation to institutionalise alleviated some informal carers' negative emotions (such as guilt) surrounding such a decision. Finally, no ATs were brought from the community to the care home to help ease the transition for newly-institutionalised care home residents. The findings help to fill the knowledge gap observed in Chapter 5 concerning whether triggers for institutionalisation of people with dementia are related to AT use, and whether decision-makers for relocation consider the role of ATs.

9.8.1: The tipping points for institutionalisation

The reasons given by interviewees for the decision to move their relative with dementia to a care home can be categorised into physical and cognitive catalysts. The reasons related to physical functioning will be discussed first. Physically, relocation was often triggered by the person's increased frailty and immobility, or an acute event such as a fall. The cognitive reasons are then presented. These included the impact of cognitive impairments leading to risk of compromised safety, such as getting lost while outside or leaving a gas oven on. However, these reasons were not necessarily mutually exclusive, and the decisions were rarely made for one reason alone. Rather, a combination of physical and cognitive factors was felt to trigger institutionalisation. Overall, informal carers felt that the presence of no currently-used or new ATs could have kept the person with dementia at home for any longer.

Informal carers reported that the physical triggers for institutionalisation related to increased frailty and immobility, which impacted negatively upon their relative's ability to perform ADLs. Although frail and immobile individuals had been receiving formal care while living at home, over time their needs increased to such an extent that it was considered safer for them to have constant formal supervision. For example, Case C became more difficult to care for as his mobility decreased:

C1: The only reason he's in [Care home #2] is because he's quite a big man he was six foot and I'm quite small and I literally couldn't manage him physically and in the end neither could the carers without hoists and things... if he could walk he could still have stayed at home with carers

Case C's reduced mobility meant that providing assistance with ADLs became extremely difficult without appropriate ATs. As already described, C1 was offered an appropriate AT of a stand-aid hoist, but refused it because she could not trust two formal carers to arrive at her house at the same time. Reduced mobility and lack of suitable ATs at home meant that Case C was at increased risk of suffering an acute event such as a fall with serious injury, thus relocation was the preferred option.

Falls were the second factor related to physical functioning which triggered an institutionalisation decision. Many of the people with dementia who were investigated had a history of falls; this was cited as a direct reason for institutionalisation for four people with dementia. Both Case M and Case N relocated directly to a care home after a stay in hospital because of a broken hip from a fall. Case B also frequently fell, sometimes during the night, and it was while in hospital that she spoke to B1 about relocating to a care home. She wanted 24-hour supervision for her safety, and felt her telecare alarm was no longer enough.

Families also indicated cognitive triggers for the institutionalisation of their relatives. They sometimes became lost while outside because of disorientation resulting from their dementia. For example, Case A began to run away from her flat because she stopped recognising it. The relocation decision for Case E was triggered because her disorientation when alone worried E1 and her sister. They perceived that she required supervision to ensure her safety. Some people with dementia were also reported to forget to turn off their gas ovens, which compromised their safety.

More typically, institutionalisation was triggered by a combination of physical and cognitive factors. For example, Case P had been getting lost in the time leading up to her relocation but the decision was also made as a result of a stroke. Case B frequently became disoriented and left her house in the night; she was worried about her own behaviour but her fall became 'the last straw'. Although Case F's major fall was cited as a particular motivating incident for the decision, her cognitive-related behaviour, such as forgetting the gas oven was on and getting lost, also contributed.

Ultimately, informal carers did not perceive that the use of any AT, or introduction of new ATs, could have kept their relative at home:

C1: I don't really think there was any aid that would have kept him at home any longer

D1: I'm not sure if technologies could have kept her there really for very long... I think there were other aspects of her life that she was finding a bit confusing and I'm not sure if technology would have helped

The only exception was D1's perception that Case D would have had to be institutionalised earlier without her complete bathroom modification. Although fall-prevention and mobility-enhancing technology was used at home by people with dementia, it was eventually felt that 24-hour supervision was required, even for Case D. It was felt that this level of supervision could not be met by telecare alarm technology, pertinently because some refused to wear the pendants, or pull the alarm cords, as they did not perceive that they required help. None of the people with dementia had an automatic gas shut-off valve in their house. However, informal carers perceived that these ATs alone would not have kept their relatives at home, given the multiple physical and cognitive functional limitations arising from their dementia and co-morbid conditions.

9.8.2: Healthcare professionals as catalysts for institutionalisation

Family members rarely made the decision to relocate their relative with dementia alone. Often the decision was prompted by a health or social care professional, following their involvement after a fall or other acute incident. For example, after being informed that Case A was getting lost while outside, her GP strongly encouraged A1 to consider relocating her mother:

A1: Mum's GP said "If you don't do something she's gonna have an accident and she'll be dead and how would you feel then"... the GP thought she might just run out one day [and get run over] he said "How would you feel if a family were involved as well it would be dreadful"

The GP used discourse about risk to persuade A1 that Case A should relocate. The underlying message was that safety was now a prime concern for Case A. Other professionals were reported by informal carers to have used similar persuasive language. For example, Case C's social worker recommended that he relocate to a care home following a needs assessment. Although the social

worker did not make the decision for Case C, she did warn C1 that she should choose this option 'before the decision was made for her' following an acute event such as a fall or second stroke. Again, the rhetoric of safety by health or social care professionals often persuaded families to decide.

The involvement of professionals was not wholly welcomed by the families of Case D and Case I. For example, although Case I had a fall her cognitive impairment meant that she could not remember the incident. It was because of this that the hospital staff perceived that she could not live on her own, or at least not without 24-hour monitoring, and that she needed to be institutionalised. I1 and her husband were not happy that this decision had been made by hospital staff, who did not know Case I's ability to perform ADLs; however, they felt powerless to disagree. Similarly, after a protracted hospital stay Case D was taken home by professionals and asked to make a cup of tea. However, she could not because she was disoriented in her kitchen having not been there for some time. The professionals then decided that Case D could not live alone. D1, who had not been allowed to say anything during the assessment, was unhappy because Case D had not been given time to reorient herself. D1 felt she had no input into the decision when it was made. There was no discussion between the family and healthcare services of the potential use of ATs to help reorient Case D in her kitchen, such as item labels or glass-fronted cupboards.

Overall however, informal carers were glad for the input from health or social care professionals, as it meant that some of their negative emotions and 'blame' for making the decision were removed. Others felt guilty about the decision even with the involvement of the health professional, as they felt they had 'failed in their job' of looking after their relative adequately at home. Particularly, informal carers looking after their mothers felt that caring was their societal duty. The decision to move was made once the informal carer realised that their relative could not cope in the community no matter how much human or technological assistance they had for ADLs, as they required 24-hour supervision from trained carers to guarantee their safety. No ATs were used to alleviate the negative aspects of the relocation transition experience, even devices which may have targeted the person's emotional distress and calmed them, such as reminiscence technology. Although people with dementia moved with some personal ATs such as their own walking stick, usually the few ATs for ADLs that had been used at home were left there.

9.9: Theme 5: Care home life

The fifth theme, entitled 'Care home life', relates to research question 5: how did ATs for ADLs used in care home settings enhance residents' care, and contribute to connections between residents, family members, and care home staff? This theme is separated into three sub-themes. First, the ADL disabilities of residents and subsequent human and technological assistance given to them are presented. Second, when ATs were not used for an ADL with a resident, the researcher discussed with keyworkers whether particular ATs would be useful. Generally, however, it was felt that there was as much technological assistance as could be given. The third sub-theme concerns family visits to residents: whether they provide any ADL assistance in such a location, whether they used ATs with their relative, and their relationships with care home staff. The findings help to fill the knowledge gap observed in Chapter 5 concerning when and how ATs are used for ADLs in care homes by people with dementia.

9.9.1: Performance of ADLs and associated AT use in care homes

The structure of this sub-theme reflects that of sub-section 9.5.1 within theme 1, wherein the ADL difficulties of people with dementia when at home were presented. The human and technological assistance given to the care home residents to help ADL performance are additionally included. First, what was reported in general about residents' cognitive and physical difficulties are discussed; specifically, disorientation, lack of confidence in groups, and immobility. The focus then turns to what was reported about poor performance, human help, and technological assistance for the ADLs under investigation: washing and bathing; grooming and dressing; toileting and continence; and feeding and eating. For all residents, the longer they had dementia, and the more co-morbidities, the greater the effect on ADL performance. This thus meant they required more human and technological assistance in the care home, compared to when they lived in the community.

Cognitive difficulties

There were two cognitive issues that were perceived to impact upon general daily life and ADL performance: disorientation, and lack of confidence in group settings. Disorientation to time and date was a common impairment among the care home residents. Formal carers reported reminding these residents of the date and time during morning routine and throughout the day. Residents were also disoriented to place. This often made them anxious and distressed, particularly if they could not locate a bathroom. The inability to find rooms was apparent even with dementia-friendly way-finding signs on doors. Staff were required to direct disoriented residents to the appropriate

location. However, Case A, who was in a less severe stage of dementia, found way-finding room signs and item labels to be helpful:

K1A: She wasn't able to locate the shower room but now [the bathroom sign] is on there she knows... [and] she can locate due to the signs on the cupboards where to put the utensils and the plates

The care home keyworkers indicated that they were in the process of creating a memory box for residents' bedroom doors. These were to contain personal items linked to the person and their history, to aid orientation to their bedroom.

Dementia also led to lack of confidence in larger groups. This was not reported by informal carers when discussing their relatives' lives in the community; of course ADLs were conducted in more private spaces at home. When living in the care homes, residents were sometimes frightened to leave their room and reluctant to socialise. This may have been linked to their inability to recall appropriate social behaviour, bewilderment when trying to follow a conversation, or intolerance of loud noises. For example, Case G always preferred to eat breakfast in her room but would emerge afterwards. Case K disliked large groups but gained confidence in the small group on the dementia ward. At other times she preferred to be in her room with her toy cat. Although residents sometimes displayed this disengaged behaviour, the interviewees indicated that in fact having peers around often made residents happier than when they had been at home:

A1: She will say to me she's a lot happier now because she used to say to me in the flat "You don't realise what it's like for me here on my own hours and hours on my own waiting for you to come"... she's got more company so she's more stimulated

Residents usually joined in with activities until their cognitive impairment hindered their language and social skills, caused apathy, or lack of understanding of surroundings. No ATs were used in the care homes to increase confidence and aid social participation, apart from the RemPod (RemPods, 2015) in Care home #1. This was the pack of reminiscence objects described in Chapter 7.

Physical difficulties

As with cognitive difficulties, as the person's dementia progressed they experienced more severe physical difficulties. The biggest issue was immobility, which deteriorated for all residents since they

entered the care home. They all required some assistance with at least one aspect of mobility, commonly gait, transferring, or balancing while sitting. Immobility was perceived to be linked to cognitive and physical impairments. Cognitively, residents had short attention spans and were unable to perceive how to move appropriately. They began to shuffle their feet when walking. Physically, immobility was linked to: joint pain, muscle weakness, or contracted legs. Eventually, some residents became so impaired they were bedridden.

Many mobility-related ATs were used in the care homes. These ATs were more sophisticated and expensive than ATs used by people with dementia in the community. As mobility decreased, the residents progressed from using a walking stick, to a walking frame, and eventually to a wheelchair. Wheelchairs were provided by the care homes. Some residents would self-propel using their feet on the floor to navigate the care home. Lap belts prevented users falling out but were not appreciated:

B1: Well she did say once or twice "Oh I want a pair of scissors so I can cut the straps on this"

Wheelchair-bound residents were hoisted with a handling sling to transfer. Although some residents were agitated when in the sling, family members were happy with the stand-aid hoists and thought they were 'amazing' and 'useful'. Keyworkers were also positive about the use of this AT:

K2B: Compared to years and years ago [the] hoist is like your best friend

The device prevented the need for formal carers to perform heavy lifting and reduced the risk of skin-tears for the residents. If residents' skin integrity was poor, they had a water-chair rather than a standard wheelchair. These were large armchair-like wheeled chairs. They were soft and filled with water to reduce the likelihood of pressure sores. Residents were measured for these by a physiotherapist, and it was usually financed by the resident or their family. The water-chairs took a long time to be made, which for Case C meant that he was confined to his bedroom for two months. Indeed, if an immobile person at risk of pressure sores did not have a water-chair, they became bed-bound and lay on a specialised inflatable mattress. Others were reported to share water-chairs; one resident had morning-time use of a water-chair and was then bed bound during the afternoon, while their 'partner' was bed-bound in the morning and had the water-chair in the afternoon.

Bedroom ATs differed according to need. Although all had a nursing bed that could be elevated or lowered, bed-rails and bumpers were only put in place if the person was at risk of rolling out of bed

and would not attempt to climb over them. If they were at risk of rolling but were perceived as likely to climb over bed-rails, extra mattresses were instead placed on the floor next to the bed. All residents had a call-alarm as standard, yet both the care record notes and interviewees suggested that none of the residents with dementia would be able to use this alarm if required. Mobile residents had a pressure-alarm mat to notify staff if they left their bed during the night. People with difficulty moving in bed were repositioned by carers using slide-sheets. Slide-sheets were two pieces of silk stitched together to enable a person to be repositioned without strain, reducing the risk of injury. There were different colour-coded sizes of slide-sheet for various body masses. Stand-aid hoists were also used to weigh bed-bound residents. The cognitive and physical difficulties residents had with ADLs once in the care homes, and the human and technological assistance given to them to aid their performance, are presented below.

Washing and bathing

In the care homes, washing was usually performed as part of morning routine. Typically, residents would have a strip-wash in their en-suite sinks, and a full bath or shower once or twice per week. Human assistance with washing and bathing began with verbal prompting, over time included some physical prompting (such as handing the person a flannel), then eventually became full physical assistance. None had required full assistance while living at home, apart from Case C. Co-morbidities such as arthritis contributed to the need for washing and bathing assistance, and particularly influenced the parts of the body that people needed help with. For example, some residents needed assistance at first with only their lower extremities due to cellulitis or arthritis, and only later the upper limbs and torso. However, the main cause for washing disablement was due to cognitive impairment, such as sequencing actions and forgetting how to perform the steps needed. Furthermore, their progressed dementia meant that residents had 'good' and 'bad' days in terms of the amount they could do for themselves and the reluctance, anxiety, and aggressive behaviours they displayed. For example, Case J and Case K could wash their upper bodies with prompting if they were lucid on a 'good' day, whereas on 'bad' days they needed more help despite their resistance. Keyworkers reported that cognitive impairments also affected residents' understanding of water temperature, using bathroom fixtures and fittings, or understanding instructions. As such, Case A was supervised during her showers even though she could perform the right washing movements:

K1A: You say "Oh if you turn the tap the cold's gonna come out first" and even though you've said it it's caught her out because she hasn't quite picked up what you were trying to communicate so you just move the shower head while she turns it on otherwise it will be cold

Full showers were conducted in a wet-room style bathroom, located on one of the main corridors. The shower rooms had non-slip tiles, coloured grab-rails against a pale wall, and a grab-frame around the shower area. They had a shower seat or commode to prevent the resident from standing for a long period of time. One of Care home #3's shower seats tilted back to aid washing. However, Care home #2 did not have showers and only had the option of a weekly mechanical bath or (more frequent) bed bath. C1 was unhappy that the care home perceived that baths were preferred:

C1: People have showers these days and all the nursing homes are geared up for baths which is ridiculous half the people can't use them because they can't get in and out... they've got a hoist to get them in a bath but obviously they can't do that every day and that's why I'm anxious that they get showers put in

Thus, the mechanical bath was not perceived as useful by C1. These mechanical baths had a large seat that could hoist the user completely out of the tub, over the rim, and safely to the floor. The hoist had a chest-level belt and moved slowly to prevent anxiety. The user remained in the seat during a bath. Case L was very frightened after a previous bad experience in a hoist so only had bed baths. Other residents enjoyed it:

K1A: She's quite happy if you ask her she'll say "Oh this is a good invention I'll have to get one of these at my house"

Bed baths were given to residents who were very immobile, had contracted legs, or had poor balance. For example, Case P could no longer use a bath because she constantly slipped downwards in it. When asked about the water used for strip washes and bed baths, K9I indicated that a traditional wet flannel was only used for the face and upper extremities. To wash genitals, keyworkers used of a type of dry wipe that could be soaped up with a little warm water. They were disposed of after use. These dry wipes had been 'hidden' technologies to the researcher, as they had not been recorded in the care records. Dry wipes are hygienic and commonly used in healthcare and care home settings, so it was unsurprising that their use was not reported in community settings by family members. Carers used slide-sheets to reposition immobile residents during bed baths.

Concerning skin integrity, most residents were at risk of experiencing pressure sores or skin-tears. Risk was caused by dry or thin skin, sweat, the acidity of urine and faeces, malnutrition and

dehydration, or remaining in the same position. Aqueous cream, air-pumped pressure mattresses, water-chairs, extra cushions, and slide-sheets were used to reduce the risk of compromised skin integrity. Case I and Case L wore blow-up booties to protect their heels from pressure sores.

Grooming and dressing

As with washing, assistance given with grooming activities such as tooth-brushing, blow-drying hair, and shaving was determined by the extent of cognitive and physical impairment. None had required any help when living in the community. By the time of data collection, some residents required verbal prompting for some tasks, if they forgot what needed to be done. As residents became less able to manage their oral-care, staff would verbally prompt, then provide full physical assistance with tooth-brushing or denture hygiene. To reduce the amount of human prompting, a sign was put on Case A's mirror to remind her to brush her teeth. However, carers still needed to charge her electric toothbrush as she would not remember to do this. The sign and electric toothbrush were the only ATs used for oral hygiene by any resident. For others, such as Case B who 'did not seem to want to do anything' even when prompted, full assistance was given. Staff found it difficult to provide assistance with grooming activities to residents who resisted. Cognitive impairment also affected residents' understanding of consequences of their decisions and actions. For example, Case H refused much-needed dental work, and Case P would hit out when eye drops were administered. The only other AT used for grooming by the residents under investigation was Case C's electric shaver. He did not like it, so it was discarded.

No resident performed nail-care on themselves. It was imperative that nails were kept short and clean, as some residents were known to scratch themselves or attempt to self-evacuate their bowels when constipated. A formal carer clipped their fingernails when needed, and sometimes varnishing nails became a social activity. All had a podiatrist for toenails and foot care. Weekly hairdressing appointments were also part of the social activities for residents.

Concerning dressing, over time the residents with dementia typically began to first show disability with putting on clothes for lower extremities, and then for upper extremities. Physically, dressing was impaired because of reduced mobility, co-morbidities such as arthritis, inflexible joints, and breathlessness on exertion. Poor eyesight and reduced dexterity contributed to problems operating zips and buttons. Carers provided assistance with 'tricky' and 'fiddly' clothes first, such as bras, knickers, and button and zip fastenings, and later with larger items such as putting on trousers and skirts. However, even physically-well residents required assistance due to their dementia. Cognitive

problems included: putting clothes on incorrectly, 'strange' combinations of patterns or colours, wearing the same item for multiple days, and not perceiving that laundry was dirty. Families would provide new clothes but their relative would not recognise the items as theirs, or would recall old items from their past that they believed had been stolen:

G1: She'll also say "Ah my certain shoes are missing they were there last week" but I know for a fact they weren't

Residents with severe dementia were unable to choose the clothes they wanted to wear, nor to detect their body temperature and make appropriate changes if necessary. Only Case G, the resident with early-stage dementia, displayed no difficulty managing body temperature or required carer assistance to control this. Carers assisted dressing all other residents, as part of the usual morning routine after washing. Following verbal instructions was sometimes difficult for residents. Staff always asked residents what they would like to wear, even if they were uncommunicative. This helped to promote a sense of dignity. Other examples of maintaining dignity included dressing bed-bound residents in day clothes, and encouraging residents to choose whether they wanted to wear shoes or slippers around the care home. However, B1 had been unhappy when the carers stopped dressing Case B in her usual tights to make toileting easier. Other examples of changes in dress included the introduction of Velcro shoes that could be widened to fit over swollen ankles, and preferring for residents to wear skirts or trousers with elasticated waists to assist with toileting.

Assistive Technologies were rarely used to help with dressing. Case G could put on her own shoes, but when her ankles were swollen used a long-handled shoehorn to make the task easier. This shoehorn was owned by Care home #3, but having owned one previously she knew how to use it. Case A had a reminder sign for disposing her dirty laundry. At least four of the residents wore hip protectors under their clothes to help cushion them if they fell. J1 and J2 described the hip protectors as a large pair of knickers with solid areas at the hips. They were glad that the device was protecting their mother. Residents were generally not resistant to wearing them but sometimes became confused about their presence. The hip protectors were usually suggested and then obtained by staff at the care homes, although they were financed by the resident or their family.

Toileting and continence

All residents had some experience of incontinence while in the care homes. Indeed, becoming incontinent was one of the biggest changes observed between living at home and living in the care

homes, as dementia progressed. Individuals with severe dementia eventually became incontinent of both urine and faeces. The most commonly-used AT for elimination was a continence pad held in place with net knickers. There were different sized pads for different body types, and for anticipated amounts of fluid. As such, the person's fluid intake needed to be monitored to determine the correct pad. Pads were provided to the care homes by healthcare services. Pads were supposed to be in place for a maximum of four hours, and there were guidelines from healthcare services as to how many pads were acceptable for a person to use during one day. However, residents were not left in wet pads just because they had reached their quota; if the care home needed more pads they would use kitty money to buy their own. Some keyworkers were critical of their colleagues' misuse of the pads, complaining that others selected the wrong size or fitted them improperly so that urine leaked. Residents generally accepted the pads:

K7G: She always says "Oh they stink" and I say "It's just them little dribbles" she goes "Oh I suppose you're right you know best"

Family members and keyworkers were happy about the use of pads because it retained some dignity for the wearer compared to an alternative of soiled clothes and compromised skin integrity:

J1: You know I have no problem... it's all practical to me she doesn't have to keep having her clothes washed she's not gonna get nappy rash it's just more pleasant

Pads needed to be checked regularly by the formal carers to see if they were wet, so still required human assistance to be effective. Use of pads ensured that clothes and skin were protected from the caustic effects of urine and faeces. Some residents also had disposable sheet pads for their beds in case of night-time accidents; these were purchased by the care home. For some residents, the assistance required was only to remind them to go to the bathroom when they could not detect their need to evacuate. Staff kept these residents to a timed routine by encouraging them to go to the toilet every two hours throughout the day. Formal carers managed the timed routine; no ATs (such as memo-minders or alarm clocks) were used to assist this procedure.

Not all residents had en-suite facilities in their bedrooms. Communal bathrooms had room labels and red doors, and were accessible from lounges, dining areas, and bedrooms. All of the care home bathrooms had hand-rails. Most toilets had a raised seat: some white, some blue, and some red. The residents found these to be beneficial when transferring onto the toilet:

K1A: She uses a raised winged toilet seat just so she hasn't got to get down so low so she can get up and down independently

Commodes were used in bedrooms if this was easier than mobilising to the toilet. Residents with more severe dementia or poorer mobility were assisted onto a toilet or commode by carers, sometimes with a stand-aid hoist. However, eventually some residents' poor balance impeded safe use of a toilet or commode:

K9I: To sit her on the toilet would be quite dangerous now... her sitting posture's terrible

If a person could no longer sit on a toilet or commode due to immobility they were classed as incontinent, along with those residents who could no longer perceive their need to evacuate. They then only used continence pads.

Others required human supervision while in the bathroom. For example, Case E was generally continent, but needed to be monitored as she would use toilet paper as a makeshift pad. She also needed to be prompted to wash her hands. Carers often 'washed' residents' hands with an anti-bacterial wet wipe:

K8H: Getting to the sink and putting her hand under the water can be a bit of a shock to them sometimes I think using a wipe is probably better for them

Thus, toileting and continence issues were managed through human and technological assistance.

Feeding and eating

As they had done when in the community, those with mild to moderate dementia were able to eat and feed themselves, and prepare drinks if required. However, over time residents would progress to a severe stage of dementia and then experienced problems with eating and feeding. Cognitively, problems included inappropriate use of cutlery, forgetting to swallow, and being distracted or resistant at the table. Disorientation to time and inability to remember recent events was common:

E1: Occasionally she forgets that they've had lunch she'll sort of say "Where's lunch" so they'll give her a biscuit to keep her [laughs] or a banana or something

Physically, damage experienced after stroke, arthritis in the hand or wrist, or reduced finger dexterity made cutting action difficult. Formal carers advised that chest infections caused breathlessness when eating and inhibited swallowing, thus impacting upon nutritional intake. Case D's stroke caused her to perceive food on only one side of the plate, so carers needed to spin it so she could see the uneaten food. As the person's cognitive and physical abilities declined, carers would feed the person:

I1: She wouldn't be able to hold the spoon herself or help in anyway other than open her mouth they put the spoon on her lip and that makes her open her mouth

Some residents had trialled and used some eating ATs before needing formal carers to assist with feeding and drinking. This was usually to add a plate rim for the person to grasp, rubber plate bottoms to prevent slipping, or plastic mugs with two handles or spout. Straws were sometimes used for easier drinking. Case D had tried an adapted spoon but no other resident had trialled specialised AT cutlery, such as those with enlarged, coloured, or angled handles. The devices that had been used were perceived by keyworkers to have been beneficial for a short time until the person's dementia progressed further and they became unable to use them.

Residents were put on a soft or pureed diet when increased cognitive and physical impairment caused chewing and swallowing difficulties:

C1: It's the brain not telling his hand to do it [use a spoon] and it's the brain not telling him to chew nothing wrong with his arms or his hands he has nothing else wrong with him except Alzheimer's

I1: She sometimes forgets to swallow she couldn't have anything that she could chew because she doesn't know what to do with the parts of her mouth

People who could not swallow were given pureed food on a spoon by carers. Drinks for these residents were also thickened and administered with a straw, spoon, or spouted cup. Finally, as their dementia progressed, residents became unable to detect when they were hungry or thirsty. This meant they refused food. Fortified nutritional drinks and vitamin or calcium supplements were commonly used to reduce the risk of malnutrition.

9.9.2: Keyworkers perceived that other ATs would not be useful

During the interviews, keyworkers were asked for their perceptions of the potential usefulness of ATs that were not used by, and with, the resident. For example, during drinking ADL a normal cup was held by carers to Case B's mouth. Her keyworker felt that a spouted lid on a cup to enable Case B to drink without human assistance would not have worked:

K2B: I don't think she's got the co-ordination to go where the mouth is

Overall, keyworkers perceived that residents were using all the technology that was possible for their situation. They felt that automated verbal prompting technology for hand-washing, or knickers that alarmed when wet, would be frightening and undignified for residents with dementia. However, K8H felt that Case H could trial angled cutlery to help her eating. Yet, there were none in Care home #3. K8H advised that to obtain this technology she would only have to discuss the situation with the general nurse who, if agreed, would ask kitchen staff to order the items. Thus, as had been observed in Chapter 8, the care environment was critical for residents' access to potentially useful ATs.

Keyworkers, like the informal carers in sub-section 9.7.2 above, were more positive about the usefulness of ATs that were designed to look 'old'. For example, they thought that a toilet with a chain flush would be familiar and thus potentially useful for those residents who could no longer use toilets with modern flush systems. Indeed, residents of Care home #1 enjoyed the RemPod items (RemPods, 2015) and the radio in the dining room designed to look from the 1950s. However, the residents themselves were not observed using the radio, only carers were seen to use it by the researcher. No ATs that were designed to look from another period of time were used for ADLs in either the care homes or community.

9.9.3: Family visits to the care home and ADL assistance

Generally, relationships between family members and care home staff were good. Keyworkers indicated that informal carers were essential for advising staff on their relative's preferences for ADL assistance. Formal carers were also generally happy for families to assist with ADLs:

K4D: It's fine she actually eats better for [D1] than she does us some days

However, they advised the researcher that families could not use the stand-aid hoist technology without training in moving and handling. Overall, it was reported that informal carers did not assist with their relative's ADLs in the care home. This was not only because staff were paid to perform these intimate tasks, but because family members were frightened of their relative's increasing frailty. Families felt that this meant they could enjoy social time with their relative again:

G1: It's more satisfying [visiting] here because it's better quality time than just feeling that you've done her washing for her [you're] taking her outside somewhere and giving her a bit of enjoyment

Family assistance with ADLs was also unlikely because visits were usually during the day after the morning routine had been completed, and outside of meal times. There were some instances where family members had helped their relative to dress or took them to the toilet themselves, but these were rare. Help if given was most typically with eating, or with the semi-social grooming activity of varnishing fingernails. Rather, families would take their relative out on day trips if appropriate, and it was at these times that they would use ATs. Wheelchairs and walking sticks were borrowed and families sometimes took spare continence pads from the care home in case they were needed. They enjoyed being able to borrow mobility-related technology as it meant that day trips were possible. F1 also borrowed a raised toilet seat to modify their home environment and thus reduce Case F's toileting disability when there:

F1: Which I found great because obviously at home not having the grab handles and so forth it was difficult but with the raised seat between my wife and I we could get her onto the toilet no problem which was very minor but people don't realise it's an amazing thing... that worked well for a while but then it became more difficult to lift her up and so forth

F1 indicated here that although the AT worked, it was only for a short time until Case F's cognitive and physical functional limitations progressed.

9.10: Chapter 9 summary

The vignettes created from Stage One of data collection acted as the skeleton structures to which interview data collected in Stage Two were added. Most informal carers were the adult child of a person with dementia, with one spouse and one niece-in-law interviewed. All interviewed

keyworkers were female. Each case study focused on one care home resident with dementia. A cross-case comparison was conducted using thematic analysis to explore common and unique experiences concerning ADL disability and associated use of ATs.

The thematic analysis enabled the perceptions of key informants to emerge from the interview data. They reported that although indeed co-morbidities resulted in immobility and pain which impeded the performance of daily living activities, they also felt that the cognitive and physical consequences of dementia had a large effect on ADL disability. Overall, informal carers and keyworkers felt that ATs for ADLs were beneficial and had the potential to promote quality dementia care in communities and in care homes. Yet, AT use for ADLs in the community and in care homes was rare. One main reason for this was that the people with dementia were reported to have negative views about the potential use of ATs, and generally felt these were not needed. Those who did receive an AT were unable to learn to use it, or maintain its use for long periods. Tipping points for institutionalisation were related very often to an acute event such as stroke or fall, or general disorientation in daily life. Then, people with dementia were perceived as no longer safe to live in the community, even with human and technological assistance.

All residents displayed more ADL disability while living in their care homes. This was inevitable as their dementia progressed over time. Even in the care homes, human assistance was more common than technological help for ADLs. When ATs were used, carers still monitored the resident to ensure their safety. Formal carers acknowledged that, for some tasks, human care was necessary or preferred. Although family members rarely assisted with ADLs in their care home visits, being able to borrow some devices enhanced their social experiences with their relative.

In Chapter 10 which follows, these findings were combined with the results of the statistical analysis presented in Chapter 6. These formed key findings to consider when promoting the use of ATs to assist ADL disability of people with dementia.

Chapter 10: Discussion

The study aim was to investigate informal (family) carers' and formal (paid) carers' perceptions of whether ATs could be used to assist people with dementia to conduct ADLs; and if so, how. This included an exploration of family members' perceptions concerning the contributory role that ATs for ADLs may play in a relocation decision. The research questions explored: the cognitive and physical difficulties people with dementia had when performing ADLs; the types of ATs that people with dementia used for these ADLs while they lived at home; informal carers' perceptions about ATs for ADLs including their preferences, barriers, and facilitators to use; the tipping points for the person with dementia to enter a care home and whether AT use, or indeed non-use, was related to the relocation decision; which ATs were used for ADLs in care home settings and whether the use of ATs for ADLs in care homes enhanced relationships. A mixed-methods study was designed to meet the study aim and research questions. First, statistical analysis of the large, nationally-representative ELSA dataset was conducted. This explored the associations between the use of mobility-related ATs and low cognitive function, ADL and IADL disability, presence of co-morbidities, and socio-demographic factors. Then, in-depth experiences of ADL disability and AT use were captured using case study strategy. The case studies were informed by both care record data of care home residents with dementia and by qualitative interviews with their informal and formal carers.

In this chapter, the key findings arising from the results from the ELSA analysis and cross-case comparison are presented, placed in the context of previous research. First, what was found about the contribution of cognitive and physical impairments and functional limitations to ADL disability is discussed. Then, the findings on ATs used to support ADL disability and immobility are presented. Particular focus is given to the barriers to AT use by people with dementia, factors that may encourage device use, and the difficulties for people with dementia when trying to maintain their use of ATs. Overall, the findings suggested that ATs could only supplement human caring, but not act as a substitute for such assistance in dementia care. The key findings also showed that ATs were rarely considered in relocation decisions. Support was found, however, for a decision-making model for the institutionalisation of people with dementia. Key findings demonstrated that families rarely conducted the intimate ADLs for their relatives once they resided in a care home, but did sometimes use ATs with them as appropriate. Generally, it was perceived that the use of ATs, however minimal, could contribute to person-centred, quality dementia care in community and care home locations.

The chapter content continues with the strengths and limitations of this research. Then, recommendations to relevant stakeholders, such as: social care providers and policy-makers, care home providers, and AT companies are outlined. The recommendations are made to further promote AT use, when suitable, among people with dementia and their informal and formal carers. Finally, directions for future research are suggested; these are based on the study findings and the experience of mapping data from care records.

10.1: Cognitive and physical difficulties impacted on ADL performance

The underlying theoretical framework to this thesis used the disablement process model to explain how ADL disability occurs in people with dementia (Nagi, 1965, Nagi, 1991). That is, their pathological state results in cognitive and physical impairments and functional limitations, which lead to disability when performing socially-defined actions in an unsupportive environment (Nagi, 1965, Nagi, 1991). Further development of the disablement process model demonstrated how human and technological assistance with ADLs can reduce the disability experienced, by targeting either the functional limitations of the person or the demands of the environment (Verbrugge and Jette, 1994, Verbrugge et al., 1997). However, rather than ADL disability per se, a key finding of this study was that the underlying functional limitation of immobility was the most prevalent issue for people with dementia.

Concerning ADLs, difficulties with washing and bathing were reported by informal carers, but difficulties with toileting, dressing, grooming, and eating were rarely cited by family members when their relative lived at home. However, people with dementia increasingly experienced disabilities with these ADLs as their dementia progressed. Therefore, by the time they came to reside in the care homes, difficulties with all ADLs were experienced. Key informants perceived that both cognitive and physical impairments associated with dementia affected ADL performance (Bennett et al., 2002).

When ADL difficulties were reported, key informants perceived that the particular cognitive processes which affected performance were: memory, planning actions, sequencing, and concentration (Beck et al., 1993, Belleville et al., 2007, Johns et al., 2009, Mihailidis et al., 2004b, Vitaliano et al., 1986, Wherton and Monk, 2008). Pertinently, poor memory was perceived to affect the person's ability to remember how to conduct the necessary activities, and the individual steps needed to complete them. However, even those people with dementia who could remember the

separate ADL task steps experienced other cognitive functional limitations, such as disorientation and inadequate decision-making. Lack of insight into their own ability and poor social skills hindered participants with dementia from recognising their need for, and requesting, human or technological assistance.

Physically, performance of ADLs among those with dementia was reported by key informants to be affected by: joint inflexibility, muscle weakness, poor balance, breathlessness, and pain. Of course, co-morbidities influenced physical impairments, functional limitations, and subsequently ADL disabilities. Yet, physical difficulties were reported by interviewees for those individuals with dementia who had no co-morbidities. The analysis of ELSA indicated that poor cognitive function was significantly associated with the use of mobility-related ATs, even when physical factors such as co-morbidities were taken into account. This supports previous research that suggested dementia itself can lead to physical impairments and physical functional limitations (Baloh et al., 1995, Buchman et al., 2007, Camicioli et al., 1999, Rosano et al., 2005, van Hoof and Kort, 2009).

The study findings demonstrated that family members rarely provided assistance with ADLs such as washing or dressing, but did conduct some IADL caring tasks for their relative such as shopping, housework, and preparing food. Generally, family members arranged for formal carers to assist relatives with the more intimate ADLs. They felt that formal services provided essential assistance, which helped families in turn to help their relative for longer; this finding supports previous research (Gaugler et al., 2000, Jarrott et al., 2005, Soldo and Manton, 1985). Further, families sought out mobility-related devices but rarely sought out ATs to assist with IADL and ADL disabilities, with the exception of incontinence technologies. For example, it was found that preparing food (an IADL) was commonly the first activity with which people with dementia had impaired performance when living at home. Instead of employing formal carers to prepare food, families could have taken the opportunity to trial ATs or to make environmental adaptations to help their relative to prepare their own food. Technologies such as: a glass-fronted refrigerator; a kettle on a swing base; a universal opener for cans and bottles; a kitchen door way-finding sign; or a calendar alarm for mealtimes may have been effective. However, families and people with dementia were usually unaware such devices and modifications existed.

10.2: Use of ATs for ADL disability

Overall, case study findings showed that AT use in community settings was generally low, with the exception of mobility-related technologies such as walking sticks, wheelchairs and frames, and telecare pendant alarms for safety and communication. More ATs were used in care home settings, but again many supported immobility rather than ADL disability specifically. The ELSA results demonstrated that people with dementia were certainly users of mobility-related ATs. Dementia-specific ATs such as orientation signs, flood detectors, or brightly-coloured versions of technologies were not used at home. The results supported previous work suggesting that AT use was influenced by more than just the appropriateness of a device, but also by personal factors associated with the potential user, his or her environment, and factors relating to the intervention (Sixsmith, 2006, Wessels et al., 2003). The barriers to AT use, factors encouraging their use, and issues with the maintenance of use are presented in the following sub-sections.

10.2.1: Barriers that prevented use of ATs

This study's findings suggested three main barriers to AT use: the inability of people with dementia to perceive their need for an AT; their reluctance to use it because it made them appear 'old'; and lack of knowledge about potential ATs they could trial. First, people with dementia were often reluctant or refused to use a technology if they were unable to perceive a need for it. This finding supports previous research (Gibson et al., 2015). Even if an informal carer perceived that an AT could assist their relative with dementia, they remained person-centred and focused on their relative's wishes as much as possible. Family members rarely insisted that their relative use an AT unless they perceived it as an absolute necessity for their safety. This is why mobility-related ATs and telecare alarms for safety were most commonly used by the people with dementia.

Second, informal carers reported that reluctance to use ATs appeared to be linked to their relative with dementia's perception that using a device would make them appear 'old'. Decorated, 'pretty' walking sticks were often preferred by people with dementia to help them feel that they did not 'look old'. Certainly, aesthetics of a technology can play an important part in encouraging its use (Gibson et al., 2014). Furthermore, appearance seems to be as important to the people with dementia as it is to cognitively-healthy older adults (Courtney et al., 2007, Häggblom-Kronlöf and Sonn, 2007, Hoenig et al., 2003, Nygård, 2008, Skymne et al., 2012, Verbrugge et al., 1997). Both these first and second barriers show that user acceptance is critical for the adoption of new technologies, even among those with dementia (Carswell et al., 2009).

The third barrier to AT use was a lack of knowledge, of the person with dementia or family member, about what devices were available to help with ADLs. Mobility-related technologies are visible in society and are well-prescribed in health and social care settings. However, family members and keyworkers were unaware of less well-known ATs that may have helped the person with dementia. This was particularly evident when discussing potential use of grooming and eating ATs, such as larger-handled, angled, or brightly-coloured devices. Family members in this study were not often in contact with an OT, social worker, or other health or social care professional that may have been able to provide appropriate ATs, or at least information on them. Edlund and Björklund (2011) also found that access to relevant information about available ATs was an important barrier to use. In this study, most ATs used by people with dementia were largely obtained via private means: either they were already owned by the family or were purchased from private companies such as mobility shops and catalogues. Generally, families bought items from mobility shops or catalogues because they were unaware that social care services could provide ATs; consequently, understanding and awareness of what was available was limited among the informal carers. Many family members in this study did not use the World Wide Web, so were unable to access information about ATs there. The findings support previous research that often users or family members have to educate themselves about what is available and pay for technologies privately, largely due to the absence of formal services (Clough et al., 2007, Gibson et al., 2015, Jensen et al., 2009).

10.2.2: Factors encouraging AT use

The barriers to AT use were described above. The findings also suggested three factors that acted as external or internal stimuli to promote AT use among people with dementia (Sarafino, 2006). These stimuli were: the persuasion of expert others; if ATs were prescribed by formal care services; and if the AT made a person feel safe and secure.

First, people with dementia who lived at home were more likely to use an AT if it had been suggested or encouraged by a health or social care professional. As the people with dementia sometimes lacked insight into their difficulties, the role of experts was important in influencing use. Many informal carers reported that their relative would not refuse to use an AT if asked to do so by a professional. Previous literature found that experts were important in influencing AT use among older adults without cognitive impairment (Skymne et al., 2012). This research indicates that this is just as important to people with dementia.

A second key factor influencing AT use was contact with formal social care services. Although lack of awareness of ATs available by such services was a salient barrier to AT use as indicated in sub-section 10.2.1 above, the findings also demonstrated that formal services were an important source of ATs (Cahill et al., 2007, Molin et al., 2007). This was particularly so for complex or sophisticated items, such as stand-aid hoists. Some individuals had free or loaned items from healthcare services such as continence pads, hospital beds, and walking frames. It was evident, however, that all had to 'push' to get what they wanted. The two informal carers who had professional experience of healthcare felt empowered to assess their need for ATs and request them from formal services; supporting previous research (Edlund and Björklund, 2011, Jensen et al., 2009). However, in this study, usually only telecare alarms and some mobility-related ATs were sourced from social care services. Yet, social care services have a responsibility to provide access to appropriate ATs to those in need (Cahill et al., 2007, Molin et al., 2007).

Mobility-related and telecare technologies were the most commonly-used devices by people with dementia when they lived at home. This suggested that a third factor in encouraging AT use was if the device was to be used for safety reasons. This was also found by Skymne et al. (2012) in their research with cognitively-healthy older adults, although they focused on memory-supporting reminder technology.

10.2.3: Maintaining AT use: a supplement to, not substitute for, human assistance

There were two key issues concerning the maintenance of AT use, even once a person with dementia was willing to trial it. The first was that people struggled to learn how to use devices that required active rather than passive use. The second was that AT use was always temporary, until the person's dementia or other co-morbid conditions progressed, and the device was no longer suitable. Overall, it was perceived that in both community and care home locations, ATs were rarely used by the person with dementia alone, and were not a substitute for human carers.

The first issue of maintained use was that the people with dementia often struggled to learn how to use an AT, or even to remember that it was present. Even on 'good days' compared to 'bad days' with respect to lucidity (a common rhetoric among the carer interviewees), people with dementia required considerable human assistance to use ATs. Technologies that did not necessitate learning (that is, only required passive use), or looked familiar, were more readily adopted. Indeed, the findings suggested that ATs designed to reflect technologies that residents may have used in the past were considered to be more user-friendly. These findings support previous work that shows

that technologies should be familiar, or introduced to a person when they are in the early stage of dementia who may be more able to learn (Cahill et al., 2007). It is stressed that this finding does not imply that people with dementia are unable to learn anything (Gibson et al., 2015, Span et al., 2013).

Second, if a person with dementia used an AT it often only contributed to their life for a short period until they became too physically or cognitively impaired to continue using it. Each person was monitored by informal and formal carers for changes in their needs and abilities (Pew and Van Hemel, 2004) so that appropriate alterations could be made to the care plan for the presence of ATs. However, there were missed opportunities for people with dementia to use ATs for certain ADLs. For example, when in the care homes the residents with dementia in this study rarely used dressing ATs, and instead received physical assistance from formal carers. Yet, devices such as long-handled dressing grabbers and elasticated shoelaces may have reduced the need for carers.

The findings demonstrated that although some ATs were being used in the community and in care homes to assist with some ADLs, ATs were rarely used to encourage a person with dementia to perform an ADL on their own. The exception to this was the sporadic use of ATs for eating in the care homes. More commonly, ATs that were used for the ADL disability of people with dementia acted as a supplement to, but not a substitute for, human assistance. This supports previous research findings on both cognitively-healthy older adults and on dementia populations (Agree et al., 2005, Agree and Freedman, 2000, Allen et al., 2001). Figure 3 in section 4.5, Chapter 4 presented four factors that could affect the potentiality of an AT to supplement or substitute carers (Agree and Freedman, 2000). The findings of this research found support for all four factors which meant that complete substitution of a carer for an AT was difficult. First and most salient were the characteristics of the older person, and the cognitive and physical impairments they had. For example, many were unable to learn to use an AT owing to poor short-term memory and inability to follow instructions. Second, an ADL was sometimes too demanding or crucial for the person to perform without a carer, or to rely on technology alone. For example, although various ATs to assist with washing existed in the care home, maintaining skin integrity was too important for keyworkers to not monitor performance and not to be involved. Third, sometimes the characteristics of carers or the caring situation hindered the potential for AT substitution. For example, many families had limited access to information about suitable ATs, or care home policies meant that staff had to be present during some activities. Fourth, the characteristics of the device were perceived to thwart substitution. For example, devices that were complex, required active use, or were not dementia-specific in design were not able to substitute for human assistance among people with dementia.

This is not to suggest that ATs had no useful role in dementia care. They were perceived by both informal and formal carers to supplement human caring and helped to: maintain meaningful and quality interaction with the person with dementia; minimise risk and injury for both the care-recipient and themselves; and delay further functional decline (Agree et al., 2005, Department of Health, 2009, Edlund and Björklund, 2011, Horgas and Abowd, 2004, Löfqvist et al., 2005, Mihailidis et al., 2004a). Nevertheless, informal carers felt that ATs could not completely substitute for human assistance. This study did not support previous research indicating that families consider ATs essential to dementia care (Bharucha et al., 2009, Edlund and Björklund, 2011). Family members also worried about the ethical use of an AT; whether its presence would prevent their relative from having social contact if it resulted in a reduced perceived need for human care. This supported previous research whereby physically-frail older adults were wary of the risk of social isolation through the use of ATs (Skymne et al., 2012). Overall, these findings highlight the importance of carers' perceptions towards ATs when attempting to promote AT use among people with dementia.

10.3: Institutionalisation decisions rarely regarded the presence of ATs

It is perceived that the provision of human and technological assistance for ADLs can reduce at least some of the underlying disability a person experiences (Agree and Freedman, 2003). It is also thought that such provision may delay, at least for a time, the person's relocation from community to care home (Verbrugge and Sevak, 2002). Given that there will always be some residual ADL disability even with assistance (Agree and Freedman, 2003), a care home relocation may be inevitable for some. In this study, it was felt that investigating decisions about institutionalisation, and the possible contributory role of a person's AT use to that decision, would increase understanding of the role of technologies in a person with dementia's life. In this section, first the key findings are presented on the background to a relocation decision, including the triggers and who the decision-makers were. Second, the extent to which findings supported a decision-making model for the institutionalisation of people with dementia (Caron et al., 2006) is discussed.

10.3.1: Triggers for institutionalisation and the decision-makers

Informal carer interviewees recalled that the institutionalisation decision was related to either becoming lost when outside or a fall. Therefore, disorientation and immobility were the cognitive and physical functional limitations that largely triggered institutionalisation among the research participants. No person with dementia in this study used a tracking technology when outside to aid

their disorientation. Falls occurred even among people who used mobility-related ATs; thus, their residual disability could be related to the cause of falls (Agree and Freedman, 2003). Once getting lost and falling occurred, ensuring the person's safety through 24-hour supervision was paramount for the decision-makers.

Informal carers reported that the decision-makers for institutionalisation were either the family members themselves, often considered by people with dementia to be the preferred decision-maker (Menne et al., 2008), or health or social care professionals. However, even if the final decision to move rested with the family it was very often instigated by the professional, which resulted in conflict with some informal carers (Burke, 2010, Dellasega and Nolan, 1997, St-Amant et al., 2012). Generally, the people with dementia rarely contributed towards the discussion regarding where to live, at the time the decision was made. Case B was the sole exception; she decided that she needed to relocate and started a discussion with her family. Informal carers more commonly reported that their relatives did not feel they needed to move, and this was because they lacked insight into their underlying and residual ADL disability (Corcoran and Gitlin, 1991). The people with dementia were reported by informal carers to verbalise their reasons for wanting to remain living at home. Their reasons were similar to those found in previous research: their wish to live in comfort, privacy and security (Hagen et al., 2004); to preserve their sense of autonomy (Aminzadeh et al., 2010); and their concerns about safety and mortality in care home settings (Drame et al., 2011).

Yet, the findings also supported previous research that some of the people with dementia's concept of 'home' became less important to them (Dyck et al., 2005). Many of the participants with dementia had already relocated to supportive housing more suited to their ADL needs, such as bungalows, one-level flats, and warden-supervised locations. Research suggests that they may have had less emotional connection to their new location, compared to people who had remained living in their family home (Lawton, 1982). Every individual's house gradually became unable to support their increasing needs without the presence of environmental adaptations, human, or technological assistance. However, informal carers perceived that the addition of new ATs to the home at the time of the relocation decision would not have prevented or delayed the decision from being made (Aminzadeh et al., 2010, Lawton, 1982).

10.3.2: Factors considered in decision-making

The data in the case studies supported the four main components of Caron et al.'s (2006) model on decision-making for the institutionalisation of people with dementia (Figure 6 in sub-section 5.5.3,

Chapter 5). These components were: the person with dementia's disability and capacity to make a decision; informal carer characteristics including their perceptions of their capacity to provide care and their relationships with other family members; the influence of healthcare professionals; and other contextual factors including formal support. Each is discussed below.

First, characteristics of the people with dementia were extremely important in contributing to the relocation decision. Supporting findings from other previous literature, informal carers certainly took the functional limitations, ADL disability, and safety of the person with dementia into account (Krull, 2013, Menne et al., 2008). Difficulty performing ADLs was noted by families to be a stronger influencer on the decision than the person's cognitive impairment alone, again supporting previous work (Horgas and Abowd, 2004, Juva et al., 1997, Wherton and Monk, 2008, Young, 2009). However, the potentiality of currently-used or potential ATs in the person's life as delaying institutionalisation were not specifically considered by informal carers when making the decision. Rather, if the trigger for a decision was a fall, any mobility-related devices in use were often then considered to be inadequate for delaying institutionalisation. Thus, the person's residual disability, that is, the disability they experienced even with human and technological assistance, was considered as contributing to the relocation decision.

Second, the findings showed that, after the trigger incident, informal carers needed to weigh up whether they themselves could provide increased support and ensure their relative's safety if they remained at home. This echoed findings of previous research (Boger et al., 2006, Habermann et al., 2009, Mihailidis et al., 2008). The contribution of informal carer characteristics to the decision was also evidenced when family members were keen to justify, unprompted, to the researcher during their interview why it would have been inappropriate to have their relative live in their home; either due to its location, their work, or other family commitments. However, informal carers did not cite their own stress or emotions as influencing the relocation decision, and so previous research cannot be supported (de Vugt et al., 2005, Gaugler et al., 2009b, Gaugler et al., 2000). The only spousal informal carer who was interviewed did speak the most strongly and passionately compared to the other family member interviewees about trying to keep her husband at home for as long as possible, replicating previous research on spousal and non-spousal carers' concerns (de Vugt et al., 2005). It should be stressed that no family member truly *desired* to institutionalise their relative, so previous research on desire to institutionalise cannot be fully supported (Gaugler et al., 2009b, Luppá et al., 2008). The role of other family members was somewhat important. Informal carer interviewees stressed how important it was that their siblings (if there were any) agreed with the decision. It was

not observed that the existence of a greater number of (adult) children delayed institutionalisation, and so support for previous literature cannot be made (Drame et al., 2011, Grundy and Jitlal, 2007).

Third, the opinions and influence of healthcare professionals were important both to the use of ATs as described above in sub-section 10.2.2, but also to trigger informal carers to consider institutionalisation. In fact, family members did not consider the relocation of care until the topic was introduced by professionals. This somewhat mirrored the behaviour of the people with dementia who would only uptake ATs once encouraged to by a health or social care professional. The presence and opinions of professionals removed some family members' feelings of guilt when decision-making.

Fourth, some contextual factors were salient. The spousal informal carer made her decision in part because she felt she could not rely on two formal carers to visit her house at the same time to operate the stand-aid hoist with her husband. Indeed, punctuality of formal carers can be more important than their manner with the care-recipient to some informal carers when judging the quality of care (Graessel et al., 2011). A second contextual factor was the care home waiting list, which restricted access and affected the timing of the relocation (St-Amant et al., 2012).

In conclusion, many complex factors were considered by the decision-makers after a potential trigger. Overall however, it appeared that ATs used for ADLs or immobility were not considered to delay a relocation of care. They could not reduce a person's residual disability to the extent that their care was manageable in the community (Verbrugge and Sevak, 2002). The exception was Case D, whom D1 perceived would have had to leave her house sooner than she did had she not had a downstairs bathroom installed. In fact, Case C's increased mobility difficulties and C1's refusal to accept a stand-aid hoist actually accelerated the decision to institutionalise.

Although it had been difficult to make the decision, after it was made families felt relieved rather than burdened or guilty as has been implied in previous literature (Wackerbarth, 1999). Furthermore, the relocation to the care home enabled some residents to once again participate in social activities (Gitlin, 2003, Golant, 2003). As long as these social activities matched their personal preferences, many residents enjoyed the companionship and enhanced quality of life in the care home (Miranda-Castillo et al., 2010).

10.4: 'Informal carers' became 'family members' again post-institutionalisation

Although previous literature suggested that informal carers would wish to, or feel the need to, carry on their carer roles once their relative relocated to a care home (Gaugler, 2005, Gaugler et al., 2004, Schulz et al., 2004), this was not found in this study. Generally, most family members did not perform ADLs for their relative when they lived at home, and this was even less so once they resided in a care home. Informal carers stated that this was not only because they did not feel it was their job to provide ADL assistance in the care home, but also because they were afraid of harming their relative due to their increased frailty. Some did provide help with eating and mobilising to the toilet in the care home, and assistance with dressing was given by a few family members if they arrived to take their relative out and their relative was not ready. Indeed, most family members' contact with residents consisted of social activities, such as day trips, chatting, mobilising around the care home's garden, or the care home's structured activities. Informal carers enjoyed being with their relative again without having to perform caring tasks for them. However, this largely meant that family member interviewees had limited knowledge of the ATs their relative used in the care home. Nevertheless, they felt positively about the presence of technologies, particularly the stand-aid hoists and slide-sheets. They recognised that such ATs provided safety for residents and formal carers.

Families' limited knowledge of their relative's ADL disability and associated AT use in the care home was low because staff rarely discussed devices with them. Only when there was a legal obligation to communicate about particular technologies, such as during completion of a Bed-Rail Consent Form, did discussions between keyworkers and families occur. There were some informal conversations with family members, particularly for continence pads or the use of the stand-aid hoist, but staff indicated no requirement to report to family members about these. In general, family members were satisfied with the care provided at the care home, and the communication they did have with staff helped them to feel less stressed (Gaugler et al., 2009a). Overall, family members were not averse to the use of ATs with their relative, particularly if they were for safety. It appears that safety was more of a concern for informal and formal carers than the ability of technologies to enable a person with dementia to perform an ADL alone and thus promote their sense of independence. This is contrary to previous research that demonstrated that family carers can be against the use of technologies for people with dementia if they perceive that AT use will reduce their relative's abilities (Barzel, 1991, Rialle et al., 2008).

10.5: Use of ATs in care homes promoted person-centred care

Keyworkers reported that the experiences and advice of family members concerning their relative was essential for planning appropriate, quality caring in the care homes. This supports previous research that suggested that care home staff involve families in advising and creating care plans, as they generally have greater understanding of their relative's life history, wants, needs, and interests (Burke, 2010). As such, the staff were able to support the resident with person-centred caring (Vittoria, 1998). Formal carers advised that they also remained person-centred and aware of the resident's history when attempting to trial a new AT with a resident with dementia. For example, staff were advised by the family to tell Case O that she was 'going for a swim' when about to enter the mechanical bath, because she was afraid of the hoist. Indeed, because the bath-hoist induced anxiety, they commonly opted to give her bed baths using the dry-wipe technologies instead. The choice to trial or use ATs in care homes was also linked to promoting or maintaining a person's sense of independence; this was most clearly evident in the uptake of eating ATs, such as plate rims and double-handled cups. By choosing to trial ATs for eating, staff aimed to retain dignity where possible, and not ascribe the residents to a 'sick role' label which may have resulted in further functional decline (Beck et al., 1997, Faulkner, 2001, Foy and Mitchell, 1991). Overall, keyworkers perceived that the use of ATs was an essential component of some ADL tasks that they assisted the resident with, particularly for toileting, and moving and handling activities for mobility and transferring.

However, ATs for grooming or dressing were not used in the care homes, except for one resident who used a long-handled shoehorn and slide-sheets to move bed-bound residents. It was evident that the surrounding attitudinal environment of the care home had a major influence on the presence and use of ATs. Staff closely observed and assisted residents with ADLs and other tasks, and identified opportunities for AT use. Yet, they also indicated both that the residents were using all the ATs they could, and that obtaining and trialling ATs required protracted procedures that were not always worth the effort. Thus, the care home environment was both barrier and facilitator when negotiating AT use in the lives of people with dementia. It is speculated whether, for some ADLs, restricted access to ATs enforced further dependence on the human carers (Woods, 1999).

10.6: Study strengths

This study addresses the multiple knowledge gaps identified through the scoping review of literature described in Chapters 3, 4, and 5 of this thesis. Four main strengths of this study are presented below. First, the mixed-methods study design contributed towards knowledge of AT use in

community and care home settings; out of the laboratory and into real-world contexts. Second, the findings of this study highlighted the importance for researchers to outline specific task difficulties within the performance of ADLs by people with dementia. Without these specifics, useful and meaningful knowledge cannot be elicited. The third strength was that the study gave voice to informal and formal carers' perceptions of the roles ATs for ADLs and immobility had in quality dementia care. Fourth, the findings challenged policy assumptions that ATs are currently and commonly used by and with people with dementia for ADLs; that they are seen by people with dementia and their carers as important for care.

10.6.1: Research on ATs moved out of the laboratory

This study brought together three types of data from four sources: quantitative data from the ELSA dataset; care record data, and interview data from informal and formal carers. This enabled the analysis on use of mobility-related ATs among people with poor cognitive function in a nationally-representative sample, and detailed accounts of the particulars of using ATs for ADLs and immobility among people with dementia. The results demonstrated that people with dementia and those of poor cognition are users of technologies. More importantly, it moved AT research out of the laboratory and into the exploration of the phenomena in its context, highlighting how difficult it can be for people with dementia to use the ATs that may help them (Fleming and Sum, 2014).

10.6.2: Detailed accounts of ADL disability were captured

The case study strategy allowed deeper insight into particular task difficulties within ADLs. For example, in Chapter 3 it was acknowledged that there was a knowledge gap concerning the specifics of ADL disability when only a broad description of 'personal hygiene' is used by researchers (for example, Gillioz et al., 2009). That is, much research failed to detail exactly what problems within personal hygiene people with dementia had. The design of this study enabled a more detailed understanding. For example, they showed that while washing and bathing required assistance in community settings, the grooming activities under 'personal hygiene' such as hair and dental care did not become impaired for the individuals with dementia until much later (and when they were living in their care home). Furthermore, within each of these tasks the main problems that were identified were remembering that the ADL was to be done (memory) and the contributing pain and physical weakness from co-morbidities. Difficulties with sequencing of tasks were, again, demonstrated much later in a person's life. This example attempts to demonstrate that researchers should specify the tasks within ADL disability. Without this, meaningful and useful results could not contribute to academic knowledge, policy-making, and social care procedures and provision.

10.6.3: Carers' perceptions of ATs were identified

A third strength was that the experiences and perceptions of family members and keyworkers, the people who actively cared for and likely had the most human contact with the participants with dementia, were allowed to emerge. It was outlined in Chapters 4 and 5 that the perceptions of informal and formal carers were missing from AT research. The findings demonstrated that although overall such individuals felt that ATs were a positive presence in the lives of people with dementia, this was less so when they thought about the experience of their relative or care home resident in particular. Results showed how ATs fit, or did not fit, into daily life and routine, and whether carers supported a technology's presence in the life of the person with dementia. Data on 'successes' and satisfaction with devices for the crucial ADLs were grounded in lived family and professional experiences. These are important to capture if the promotion of ATs in dementia care in community and care home locations is to work, beyond the moving and handling devices that must be used under legislation.

10.6.4: Study contribution to policy context

This study focuses on identifying the ATs that are currently being used, and not used, in community and care home settings. This is especially important given the policy context discussed in Chapter 2, whereby ATs (although mostly telecare and telehealth devices) are already championed as cost-effective and person-centred components of social care (Department of Health, 2012a, Department of Health, 2009). These policies are underpinned by assumptions that stakeholders and the public are on board with AT use, that health and social care professionals promote ATs, and that devices can be beneficial for all if only they choose to use them. The findings of this study challenges these assumptions given that minimal use of ATs for ADLs amongst the people with dementia who participated were found. Moreover, the findings highlight the difficulties those with dementia and their informal carers face when trying to obtain information about ATs through adult social care services. Thus, this study highlights that a key aim of governmental policies and campaigns for technologies to be used to provide meaningful social care, such as the Prime Minister's Challenge on Dementia 2015-2020 (Department of Health, 2015), may not yet be met.

However, the policy context is constantly undergoing change. Since data were collected for this study, there has been movement towards an integrated health and social care model throughout England. This is in response to an ageing population with often co-morbid and complex needs including dementia, requiring simultaneous assistance from both health and social care services

(Alzheimer's Society, 2014b, Bate, 2017). Currently, organisational boundaries can cause unnecessary difficulties because of duplicated assessments, support gaps, a lack of a lead professional, and delays in care due to funding disputes (Alzheimer's Society, 2014b). The future aim is to create a system whereby the different care providers are integrated, and improve the quality of care (Alzheimer's Society, 2014b). This integration model is rooted in NHS England's Five Year Forward View for the period 2016-2021 (NHS England, 2014). National aims include improving care quality and saving money by preventing emergency hospital admissions (Bate, 2017). Local aims specific to people with dementia mirror the Prime Minister's Challenge on Dementia 2015-2020 (Department of Health, 2015) and include a two-thirds diagnosis rate for dementia and improved post-diagnostic support. The Better Care Fund, launched in April 2015, is the primary funding mechanism for the integrated model by requiring local health bodies and LAs in each area to pool funding and produce plans for joining services. New models of care are currently being piloted in 50 vanguard sites with expected outcomes of £900 million in savings by 2020 and improved patient outcomes (National Audit Office, 2017).

A recent report by the National Audit Office (2017) indicated that integration was slower than expected, and the Better Care Fund had not demonstrated value for money in terms of savings made or national patient benefits. At local level, there were improvements in the proportion of older people who remained at home following hospital discharge. The Government's Spending Review published in 2015 had set the expectation for health and social care to be integrated by the year 2020 (HM Treasury, 2015); however, the recent National Audit Office (2017) report stated that this was now in doubt. Governmental documents on integration acknowledge the role of telecare and telehealth to enable faster communication and personalised care, and guidance exists for commissioners on these technologies (NHS Commissioning Assembly, 2015). Assistive Technologies are not new, and yet in this study limited use and satisfaction with devices, even telecare, was identified. This highlights more work to be done in the research, policy, and social care fields.

10.7: Study limitations

This section addresses six limitations that potentially affected the study fieldwork, quality of the findings, or ability to explore the research questions. They are presented in chronological order as they arose throughout the project: communication with the care home staff prior to recruiting participants; the procedure to liaise with family members who acted as a Personal Consultee (PC); reliability of care record data; observations during data collection about appropriate language

concerning ATs; the representativeness of the study participants; and the subjectivity of case study strategies. Although these potential limitations are valid and may have affected the conduct, effectiveness, or outcomes of the study, all were addressed by the researcher in an ethical and appropriate manner as each situation permitted.

10.7.1: Care home staff and the Data Protection Act (1998)

The first issue was that the care home employees were apprehensive about how the researcher and the study design would comply with the DPA (UK Parliament, 1998). The care home staff administrators and managers had completed training on data protection and confidentiality, but had no knowledge of Section 33 of the DPA which relates to the conduct of research (UK Parliament, 1998). Lack of knowledge about Section 33 meant that staff were reluctant to share information necessary for the project including: the names of residents with a clinical diagnosis of dementia, their family members' names, and contact information. The staff feared that providing such information would contravene the guidelines of the DPA.

The researcher consulted both Section 33 of the DPA and the Freedom Of Information Act (2000) (UK Parliament, 2000) to advise care home managers and staff that the study was legal and ethical. Under the guidelines, personal data may be gathered from 'third party' sources for the purposes of research where the data is not publicly available, and when the personal data are to be held only to enable the study to be conducted and not to inform the findings. For example, names would only be taken in order to facilitate communication between the researcher, resident with dementia, and their informal and formal carers. Therefore, such personal data were not to be treated as 'processed' under the DPA. Furthermore, the information was not to be used to support measures or decisions with respect to particular individuals, and unlikely to cause substantial damage or distress to the research participant. Finally, as the DPA and ethical obligations require researchers to be open about how they handle personal data, the information letter sent to potential participants would inform them that the research team would not keep their address (and would only view it at the care home in order to address envelopes), and that other personal information such as names and telephone numbers would not be held in the same location as their research data (so that a match could not be made between who they were and what they had said). Moreover, any information held about them would be locked in a filing cabinet and destroyed after seven years. To reiterate, the participant's personal data such as their name, address, and telephone number were only to be used to identify and contact potential study participants and not to inform research findings.

However, despite making staff aware of this, they remained unsure and reluctant to provide the necessary information for the research. Instead, care home administrators addressed the envelopes themselves. As a result, the researcher did not know who and how many people had been contacted until replies from such individuals were received, and did not even know how many residents with dementia were in each care home until the administrators later provided a list of names for the capacity-to-consent assessments. This caused a potential study limitation, because it was not known whether care home staff provided a complete list of all eligible residents, or whether some selection occurred. This led to three potential sources of bias. First, administrators may have decided that some families would not want to participate, so may not have posted the study information to them. Second, family members who contacted the care home office to discuss the study may have been given inaccurate information of the study from the administrators or managers. Thus, they may have decided to opt out of the project based on incorrect information. Third, some families received the PC letter and telephoned the care home to indicate that their relative would not want to participate in the study had they the capacity-to-consent. However, it is possible that these family members had only intended to inform the administrators or managers that they did not want to be a PC, rather than they were acting as a PC for their relative. Then, these messages could have been incorrectly interpreted and reported back to the researcher. That is, the message was supposed to be for the researcher to identify and approach a different PC for their relative, not that the resident with dementia was to be excluded completely. If a list of eligible residents and contact details of family members had been made available to the researcher at the beginning of fieldwork, it would have simplified the process and reduced these potential sources of bias.

Finally, it should be noted that the care home charity was unusual in that it had an investment in dementia research and ensured all staff were taking qualifications in dementia-specific care. The organisation also part-funded the project and provided gatekeeper access to its four care homes. Some past members of the charity had also historically been involved with the researcher's academic department. The organisation also moved away from care home management to focus on community care during the final write-up phase of this study. As such, when an executive report of this study was presented to the board, recommendations had to be adapted for community rather than institutional-based dementia care.

10.7.2: Personal Consultee procedure

The second potential study limitation was that the PC consultation process was arduous and confusing for family members, even with both written and verbal explanations. As was indicated in sub-section 10.7.1 above concerning potential administrator bias, there was the potential that some family members answered 'No' on the Personal Consultee Form or in telephone liaison with the care home administrators but did not in fact mean that their relative would not want to participate, rather that they did not want to act as a PC. Although the PC process advised by the MCA (UK Parliament, 2005) both protects vulnerable adults and enables them to participate in research, it was possible that more potential participants with dementia dropped out of the study than would otherwise have been the case had the family liaison process been simpler.

10.7.3: Reliability of care record data

As indicated in Chapter 8, there were multiple inconsistencies between and within the care records, the informal carer interviews, and the keyworker interviews. For example, a care record may have been out of date, and some informal carers had limited knowledge of the ATs used by their relative in the care home. These may have limited the reliability of the data and affected the researcher's understanding of how people with dementia actually experience ADL disability and associated AT use. Observations of residents with dementia may have provided the most accurate data on AT used for ADLs in care homes; however, due to the extreme personal nature of the activities this would have been very intrusive and may not have gained ethical approval. Furthermore, this project focused on informal and formal carers' perceptions of the role of AT for daily dementia care rather than observing users in action. It was felt that the amalgamation of the three qualitative data sources (care records and two key informant interviews) enabled the most accurate and representative picture possible.

10.7.4: Accessible language when discussing ATs

A fourth potential limitation was the observation that certain terms used to refer to ATs or other important concepts sometimes presented barriers for potential participants to understand the project or the research process. For example, during capacity-to-consent assessments residents with dementia were not always familiar with the term 'care record'. Although the Resident Information Sheet had a colourful picture of a file binder to help illustrate the meaning of 'care record', it was only during one capacity-to-consent assessment which was observed by a keyworker that the researcher was advised to say 'your big blue book'. From then on, the researcher was able to use this terminology in subsequent capacity-to-consent assessments.

Interviewees also struggled to understand the term 'Assistive Technology' and to what it referred. From then on, other words and phrases were used by the researcher to facilitate understanding, such as: 'devices', 'technology', 'gadgets', or simply 'things'. This experience has implications for the language used in AT research when engaging with participants. Academics, health and social care professionals, and AT companies may need to reconsider the terminology commonly used.

10.7.5: Representativeness of participants

The fifth potential limitation concerns the representativeness of participants. Two issues are addressed here; that only one spousal informal carer was interviewed, and that people with dementia were not interviewed.

First, most of the informal carer interviewees were adult children, and only one spouse and one niece-in-law were interviewed. That the views of spouses and other family members were not 'represented' may have been a potential limitation in this study. However, the aim of the case study strategy was not to obtain a representative sample of informal carers (Yin, 2003a), such as an equal number of adult children and spouses. Rather, the aim was to purposively select care home residents of interest to form case studies for comparison (Stake, 2000, Yin, 2003a). Certainly, it was hoped following the pilot study that multiple spouses could be interviewed, as they would have been able to contribute different experiences and perspectives compared to adult children carers concerning community-based AT use and care home relocation decisions. Research discussed in Chapter 3 identified spouses as less likely than other types of informal carers to use formal care services because they would prefer to provide care without assistance (Pickard et al., 2000, Robinson et al., 2005a, Sussman and Regehr, 2009). Spouses are also less likely than adult children to institutionalise their partner with dementia as they would prefer to age-in-place at home together (de Vugt et al., 2005, Estes and Swan, 1992, Freedman, 1996). For the topics of interest in this study, spouses may have assisted with ADLs in different ways to other types of informal carers, such as by being more involved with continence care than adult children. Spousal carers may also have had different perceptions of the role of ATs in ADL assistance, or over- or under- estimated the benefits of devices compared to other informal carers. Indeed, Case C's wife C1 indicated that the thought of using a stand-aid hoist at home was a factor in the institutionalisation decision, whereas the interviewed adult children did not report considering AT use. However, of the 10 residents who formed case studies in this study, only one had a living spouse. This spouse was the wife of the only participating male resident with dementia; the other nine were widowed females. This is to be

expected given the gender gap in life expectancy (Newman and Brach, 2001) and that unmarried (single, widowed, or divorced) people with dementia are more likely to be institutionalised (Luppa et al., 2008). Moreover, other work suggests that spousal carers of men with dementia are more able or willing to care for them at home for longer than spousal carers of women with dementia (Bartlett et al., 2016, Dorin et al., 2016, Forbes et al., 2008). Thus, the only available spouse was interviewed in this study. Nevertheless, it is recognised that this study's findings related to informal carers are largely reflective of the perceptions of adult child carers. A future direction for research could focus on perceptions of ATs among spousal carers with a partner with dementia in care home.

A second potential limitation on the representativeness of participants was that the voices of people with dementia were excluded. The study design captured the perceptions of informal and formal carers with respect to the role ATs may play in dementia care in community and care home locations. These carer perceptions were centralised around an individual with dementia, and included particularised, retrospective experiences. The aim was to follow the person with dementia's experience with ATs in a time sequence: from life in the community, through the relocation transition, and to their life in the care home. The original design did not set out to exclude people with dementia in interviews per se, as vulnerability and lack of capacity are not reasons for excluding people with dementia as research participants (Iphofen, 2009). In Stage One of this study, direct communication with people with dementia was made during the capacity-to-consent assessments concerning the decision for their care record data to be mapped. Only one of 39 of these care home residents was assessed as possessing capacity-to-consent to this decision. Many of the remaining 38 were catatonic, bewildered, aggressive, or unable to follow the conversation during these assessments. Were these residents to participate in Stage Two in-depth interviews, they would have been subject to a second assessment to assess their capacity-to-consent. It cannot be stated that each resident would have definitely have been unable to be interviewed without having been subject to a capacity-to-consent assessment for this decision (UK Parliament, 2005). However, requiring potential participants with dementia to undertake another capacity-to-consent assessment and an interview was perceived by the researcher as potentially distressing for residents. Thus, carer perspectives were the chosen sources of data for Stage Two as the severity of the residents' dementia at the time of contact may have made interviews difficult or even impossible. Furthermore, the exploration of informal and formal carer perceptions on ATs for ADLs was desired given that the scoping review of the literature demonstrated that their views have largely been excluded in AT research (Innes, 2009), even though they are often the gatekeepers for the use of such devices. Nevertheless, there is a corresponding discussion in section 10.9 below on future

directions arising from this study which highlights the potential for including the voices of people with dementia.

10.7.6: Case study criticism

A sixth potential limitation was that case studies have been criticised for being subjective and non-generalisable to wider populations (Lincoln and Guba, 2000, Tellis, 1997). However, case studies are not intended to represent ‘the general’, but ‘the particular’ (Bergen and While, 2000, Schofield, 2000, Stake, 2003). Multiple case studies do not ‘sample’ from the existing population, but select small numbers of individuals to focus on. Each case study is an attempt to portray a meaningful representation of what the key informants deemed to be true; more important to them than the objective ‘truth’ (Burns, 2000, Simons, 2009). Suggested recommendations for stakeholders are provided below. However, advice states that generalisations from case studies are largely at the discretion of the reader, and not the writer (Burns, 2000, Denscombe, 2010).

10.8: Recommendations to stakeholders

The following recommendations were shaped by the key findings. It was found that people with dementia rarely used ATs for ADLs, yet multiple devices were available for use at that time from LAs and private sources. Thus, there were barriers concerning the advertisement of these devices, the information provided on suitable technologies, or possibly the cost of these ATs and environmental modifications. It was felt that rather than designing more sophisticated technologies, focus should be on the process of getting information on currently-available technologies and the provision of suitable ATs to potential users and carers. The following recommendations are split into suggestions for social care providers and policy-makers, care home providers, and AT companies. Such organisations have a responsibility to promote awareness of available ATs for ADLs; assist people with dementia and their families to trial ATs they may find useful; and help formal carers and social workers provide this information to people with dementia and their informal carers.

10.8.1: Social care providers and policy-makers

The findings suggest that low use of ATs in community settings was related, at least in part, to a lack of knowledge of what was available. Revised, proactive policies for relevant social care services and professionals could fill this gap (Bossen et al., 2015). They should follow the joint working and multi-disciplinary approach suggested by the Housing Learning and Improvement Network (Bonner and Idris, 2012). Suggestions for changes are set out below.

It is recommended that LAs, Clinical Commissioning Groups and other appropriate bodies revise the local procedures for OTs and other health and social care professionals to assess individuals' need for ATs in their homes. This is because the provision of ATs should be early in order to increase acceptance and use by people with dementia.

There is an opportunity for the bodies mentioned above to provide more free (or subsidised loans for) ATs or environmental adaptations to promote use in community settings. Furthermore, as the findings showed use of ATs over extended periods was limited, it is recommended that the prescribing professionals schedule follow-up visits to ensure and observe opportunities for alternative ATs (Gibson et al., 2015).

It is also recommended that formal care services should train formal carers to be sensitive about the logistics of providing caring services to people with dementia. Attention should be given to understanding the importance of routine, ensuring clients eat food prepared for them, and be aware of language barriers and other communication problems. These may all hinder AT use. Similarly, it is suggested that formal carers be trained to identify opportunities for AT use to meet ADL needs when caring for people with dementia. Formal carers should feel empowered to suggest ATs to the care-recipient and their family members. Indeed, since the data for this project were collected, Skills for Care and Development launched a project to develop a national learning strategy and skills set for the social care workforce around working with ATs (Technology to Care, 2014). The scheme is underpinned by the person-centred approach to care. However, the focus remained on telehealth, telecare, smart, and electronic devices rather than simple, stand-alone ATs.

It is also suggested that statutory bodies deliver a public information campaign to promote the benefits and positive aspects of relocating to a care home. This could focus on the reduction of risk and maximised sense of independence within a safe environment. Sensitive language should be used to help informal carers understand that moving their relative to an institution does not mean that they have 'failed their relative'.

10.8.2: Care home providers

Recommendations to care home providers may enable such organisations to strengthen their strategic development such as connecting with and supporting their local community. They may also improve staff training on ATs. The recommendations are set out below.

The findings demonstrated that care home staff and families rarely discussed residents' AT use, unless required to by law, for example when introducing bed-rails. Care home providers should promote an open line of communication between staff and families on decision-making with regards to changes in dementia care for ADLs and new use of ATs with a resident. This would help family members to feel involved in their relative's dementia care, if they wished.

It is recommended that care home managers keep up-to-date information on available ATs in accessible and public locations such as lounges, receptions, and staff rooms. Care homes should empower both staff and families to think creatively about each individual with dementia's person-centred care package, and to identify opportunities for AT use throughout their life. By creating a culture that promotes AT use, this may encourage residents, staff, and family members alike to be aware of, and feel able to, trial appropriate devices.

The care homes in this study employed no dressing or grooming ATs with the residents with dementia, except for one individual who had a long-handled shoehorn. It is recommended that care homes trial the use of dressing and grooming ATs with residents with dementia, to promote the individual's performance of these ADLs for as long as possible.

Care homes have an opportunity to be a hub for their local community. They could host partnership events with other organisations, such as social services and AT companies, for people residing in the local community to view and learn about ATs that may be useful for anyone with ADL disability.

10.8.3: Assistive Technology companies

The findings showed that accessing useful ATs was a low priority for people with dementia and families in comparison to the need to access formal carers. Yet the lack of public knowledge about ATs available for ADLs, and particularly dementia-specific ATs, contributed to their lack of interest. Suggestions for AT companies are listed below.

The first recommendation is to ensure widespread advertisement on ATs for ADLs, particularly dressing and eating aids, in community settings. Companies should consider how information on ATs may reach people who have no contact with a social worker, OT, or other care professional. Leaflet drops at suitable locations such as: community centres, libraries, churches, doctors' surgeries, memory clinics, dementia cafes, and carers groups could be useful (Wright et al., 2006).

In addition to advertising to the general public, there are opportunities to provide more education to relevant health and social care professionals on accessible and appropriate ATs. Technology companies should target GPs, OTs, policy-makers, LAs, and formal care services to promote a wider variety of ATs that may be used in community and care home settings.

Companies that make and distribute ATs can do this by hosting targeted information sessions in local settings such as care homes, sheltered housing, and community centres. These could be aimed at people with cognitive and physical impairments, families, and care home providers. These sessions could provide examples of devices and allow them to be trialled for a time by potential users. However, there may be a danger that these turn into aggressive marketing campaigns.

Companies should endeavour to design more devices tailored for the particular needs of people with dementia, while allowing them to remain attractive and desirable to reduce the likelihood of resistance. They should explore this study's finding that people with dementia may be more receptive to using technologies designed to look like those they may have used in the past. Most importantly, they should co-design with the experts: individuals with dementia.

In summary, the recommendations may promote wider use of ATs for ADLs by people with dementia. However the findings demonstrated that some resistance towards AT use was attributed to fear of being seen as old and dependent. Until ATs are more accepted in society, their prevalence may remain low. Furthermore, it is not assumed that these recommendations will reduce barriers for all, as each individual's experience of cognitive and physical impairments is unique. Therefore the ATs that are useful for one person may be unsuitable for another (Mann et al., 1993).

10.9: Directions for future research

This study included informal carers' retrospective accounts of ADL performance and related AT use and the journey from residing in the community to a care home. Future work on this topic could have a prospective, longitudinal focus. That is, people diagnosed with dementia who currently live at home could be targeted and followed over time, in whichever locations they reside, to investigate how their disability and AT use changes. Meaningful understanding of ADL disability may be gained by viewing the person with dementia's home environment, rather than relying on a description from the perspective of their informal carer, as occurred in this study. This may also ensure a more

accurate count and observation of ATs used, instead of relying on carers' memories. Furthermore, any institutionalisation decision could be observed in real-time, though it is recognised that this may be inappropriate for such a sensitive experience. Continuing with a case study strategy will ensure the particulars of each individual's story remain captured. The number and type of data collection methods could be widened to include: observation; interviews with people with dementia; data mapped from community-based care records; and field-notes on the ATs and environmental modifications used. The triangulation of these multiple, complementary sources of data evidence would increase the reliability of each case study (Tellis, 1997). Furthermore, the first-hand perceptions and experiences of people with dementia may provide a strong rationale for the stakeholders discussed above in section 10.8 to change their relevant policies and procedures.

A future project could also focus on the role of relevant gatekeepers for providing ATs: shadowing social workers, OTs, and other social care professionals, including formal carers and charity case workers, to investigate how ATs for ADLs are prescribed and supplied. More work is needed on: the extent to which people with dementia and their family members are involved in the prescribing process; health and social care workers' restrictions, financial or otherwise, on supplying ATs to people who require them; and for how long people who have received ATs are kept under the caseload of the professional to ensure maintained use of a device (Gibson et al., 2015).

Although the language throughout this thesis and previously published research refers to the person with dementia using an AT, the findings showed that many ATs were rarely used by the person with dementia alone. Only mobility-related ATs such as walking sticks and walking frames were used without human assistance; devices for ADLs were used with a carer. This was particularly evident in care homes, with the exception of plate rims. Future research could explore who the user of an AT truly is and to whom its use brings the most benefit: the person with dementia and their increased sense of well-being; the family member who encourages its presence in their relative's life and feels less stressed; or the formal carer whose time is saved.

The findings indicated that ATs did not contribute to the triggers for institutionalisation, decisions for relocation, or ease of transition. Nonetheless, it is felt that more investigation is needed on this topic to fully explore whether ATs used at home could delay a relocation of care. However, survey and statistical research methods on such a complex topic do not necessarily allow in-depth reasons for institutionalisation to be identified, and experiences to emerge. Furthermore, the underlying methodological approach in this thesis is that every person with dementia is different. Therefore,

more particularised accounts of institutionalisation triggers and decisions are needed from informal carers and people with dementia themselves.

Informal carers referred to care home fees during interviews and in informal conversations with the researcher. Some also mentioned the negotiations between the caring dyad as to which of the two would pay for a privately-purchased AT. For example, G1's father used his Attendance Allowance to buy continence technology, whereas J1 and J2 paid for their mother's non-slip shower mat themselves. As such comments were irrelevant for the study aim and research questions, these data were excluded from the analysis. However, cost is clearly a salient issue for families (Pollack, 2005). The interview transcripts may be analysed in the future, to explore discourse around paying for ATs.

A final possible direction for future research relates not to the study findings but the methods. It was found during Stage One of data collection that care records held a plethora of documents and forms about each resident's health and social care plan. It was necessary to create an organisational framework to enable clear presentation of the data. The organisational framework is presented in Chapter 8. In the future, this framework could be developed further as a data collection tool. This could prepare researchers who intend to map care records for the wealth of data within, structure their organisation of such information, and aid their analysis of contents.

10.10: Chapter 10 summary

This study provided an original contribution to knowledge concerning technological assistance for the ADL performance of people with dementia in community and care home settings. The contribution of multiple cognitive and physical impairments and functional limitations were explored to understand how ADL disability occurs in this population. It was determined that ATs were rarely used to assist ADL performance. Rather, the most commonly used ATs were for safety reasons, or to manage immobility. There were many barriers to device use in community settings, mainly because people with dementia could not perceive their need for one, or could not learn to use an unfamiliar technology. Indeed, AT use among the people with dementia was more common when used in conjunction with a human carer. Most of the ATs used by people with dementia in this study occurred in care home settings, and were used to supplement assistance from care home staff. These devices again overwhelmingly related to mobility limitations. However, according to the disablement process model which acted as the theoretical framework to this thesis, immobility is a key functional limitation as it underlies the performance of all ADLs (Nagi, 1965, Nagi, 1991,

Verbrugge and Jette, 1994). Thus, findings on preferences and barriers for mobility-related ATs were still useful. Recommendations and directions for future research based on the findings include: improving the fit and design of ATs to people with dementia; improving the availability and quality of information on ATs; and promoting awareness among families about the ATs that are available.

Afterward

In this chapter, I briefly outline my academic and personal story concerning my contact with people with dementia. I also acknowledge the inclusion of the self in qualitative analysis.

History

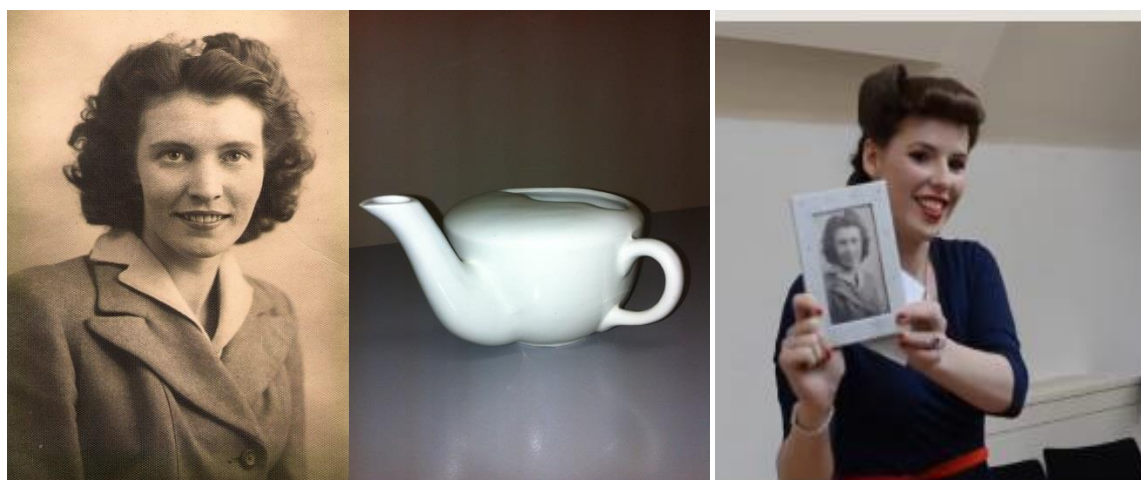
I have always been interested in older adults as a research population. My dissertation topic for an MSc Health Psychology degree concerned the exercise and physical activity motivations of adults aged 50 and older. The study had a mixed-methods design. A multiple regression analysis was conducted to investigate the predictive value of gender, age, co-morbidities, ADL difficulties, and body esteem on the physical activity undertaken by participants. Results showed that both being concerned about appearance and having a high number of co-morbidities was significantly associated with a person's level of physical activity in the previous week. Data from nine focus groups were also analysed using a grounded theory approach to explore factors influencing motivations to exercise (Hardy and Grogan, 2009). Results again highlighted the importance to older adults of maintaining good appearance and preventing health decline as key motivations for physical activity. This supports some findings in this thesis, whereby people with dementia were concerned that using ATs would make them look 'old'.

Having gained the MSc, I then worked as a Research Assistant in the Centre for Ageing and Mental Health at Staffordshire University. Both there, and during some independent research work, I learned more about dementia through particular projects: evaluation of a Dementia Support Worker service, research on memory clinics, and evaluation of a befriending service for people with dementia. At this point in my life, I also volunteered at a local charity 'Monthly Alzheimer's Support Evening' (MASE, 2010). This group aimed to reduce isolation and break the taboos and stigma associated with dementia by bringing people together for social activities. Witnessing for the first time the impact a familiar and emotive piece of music can make to a person with dementia will never leave me.

After working at the research centre for two years, I felt ready to undertake a PhD. Having secured the 1+3 ESRC CASE studentship, I moved to London and sadly had to leave the MASE group. While at King's College London I found a passion for ethical issues and research project design, so participated as a student member of a Moderate-Risk Ethics Committee. I also studied the research sub-sections

of the MCA (UK Parliament, 2005) in great detail, and have been an invited speaker at a number of events at other universities to advise on these guidelines.

The event that will stand out to me the most during my PhD was my participation in public engagement training and entering a public engagement competition. For my PowerPoint and jargon-free presentation I used props to connect with the audience. I dressed in 1940s clothing and showed a picture of my grandmother in 1947, aged 21. I told a story, based on extracts from my research data, of an isolated and frail older woman with dementia who had much ADL difficulty but no human or technological assistance. I described how she became more disabled and had to be institutionalised. I then presented my other grandmother's old porcelain cup with sipping-tube (it sits on the windowsill in my PhD office for motivation). I told a different version of the story which included the use of ATs for ADLs, to demonstrate the technological opportunities that could have been presented to the lady. I won first prize in the competition. The public engagement training was invaluable in understanding how to connect with any type of audience. I carried this forward and created an event for PhD students and early-career researchers to practice public engagement style presentations.



Although I like all aspects of research, I most enjoyed the fieldwork for this study. Negotiating and liaising with care home managers was an interesting exercise. Being present in the care homes and meeting residents, interviewing carers, and being roped in to help with an afternoon tea event were most gratifying. I missed such contact once my fieldwork was completed, so on transferring registration to writing-up status I began to work as a Dementia Support Worker for Alzheimer's Society in Southwark, London. The post fulfilled my need to see the direct benefits of my assistance

in people's lives, and I could also directly observe how ATs were used in the local community. This balanced well with the slower process of achieving impact through research. I have now moved to an Evaluation Officer post in Alzheimer's Society. For this, I can contribute to ensuring that the frontline services the charity provides to people with dementia and their informal carers have value and impact. I also consult on evaluation of other Alzheimer's Society activities which currently include: fundraising and awareness events; the youth engagement stream of work; the commitment to organisational co-production with people with dementia; and the research partnerships scheme.

Subjectivity in analysis

At times during the informal carer interviewees hearing family members' stories was heart-breaking and difficult. I feel that my personal experience of the progression of a family member with dementia made me a more empathetic interviewer. The fieldwork for this research made me address some of my perceptions. For example, I had always assumed based on 'common knowledge' that remaining at home was the ideal situation for people with dementia. The stories I heard in interviews certainly challenged my thoughts about the 'best' dementia care location.

The design of the study and the research questions determined the data collected and the choice of analyses. I see merit in mixed-methods research design to explore complex social phenomenon (Rossman and Wilson, 1985), such as dementia, ADL disability, and AT use. Concerning the qualitative case studies, it was felt that a thematic content analysis was most appropriate as the research questions required specific answers (Braun and Clarke, 2006). Furthermore, the thesis was exploratory: a more interpretative qualitative analysis was not chosen as the aim was not to create a theory of the AT use of people with dementia. However, as a critical realist I acknowledge that, despite the aim of an objective analysis, it is never completely possible to remove elements of the analyst from the process (Flick, 2014). Qualitative analyses can only be conducted from my perspective, which is informed by my experiences, beliefs, and social values. Finally, my realist epistemological perspective assumes that there is a direct relationship between the language of interviewees and meaning. Thus, I believe that as individuals with dementia have different experiences, researching the particular through case studies, rather than the general, provides the strongest understanding of people's experiences of living with dementia.

References

- ABBOTT, C. 2007. Defining assistive technologies - a discussion. *Journal of Assistive Technologies*, 1, 6-9.
- ABRAMS, R. C., NATHANSON, M., SILVER, S., RAMIREZ, M., TONER, J. A. & TERESI, J. A. 2016. A training program to enhance recognition of depression in nursing homes, assisted living, and other long-term care settings: description and evaluation. *Gerontology and Geriatrics Education*, 8, 1-21.
- ADAMS, S. 2015. Disabled Facilities Grants: a system of help with home adaptations for disabled people in England: an overview. London: Care & Repair England.
- ADAMS, T. & BARTLETT, R. 2003. Constructing dementia. In: ADAMS, T. & MANTHORPE, J. (eds.) *Dementia care*. Great Britain: Arnold Publishers.
- AGE UK 2012a. Care in crisis: seven building blocks for reform. London: Age UK.
- AGE UK 2012b. Personal budgets in social care: a new way to arrange your care and support. London: Age UK.
- AGE UK 2012c. Your home: your guide to services and equipment. London: Age UK.
- AGE UK 2013a. Care at home: getting help to live independently in your own home. London: Age UK.
- AGE UK 2013b. Disability equipment and how to get it. London: Age UK.
- AGE UK 2013c. Economic tracker. London: Age UK.
- AGE UK 2013d. Funding repairs, improvements and adaptations. London: Age UK.
- AGE UK 2013e. Paying for care and support at home. London: Age UK.
- AGE UK. 2015. *Social care funding changes* [Online]. <http://www.ageuk.org.uk/home-and-care/care-homes/social-care-funding-changes/care-cap-and-means-test-changes/>.
- AGREE, E. M. 1999. The influence of personal care and assistive devices on the measurement of disability. *Social Science & Medicine*, 48, 427-443.
- AGREE, E. M. & FREEDMAN, V. A. 2000. Incorporating assistive devices into community-based long-term care: an analysis of the potential for substitution and supplementation. *Journal of Aging and Health*, 12, 426-450.
- AGREE, E. M. & FREEDMAN, V. A. 2003. A comparison of assistive technology and personal care in alleviating disability and unmet need. *The Gerontologist*, 43, 335-344.
- AGREE, E. M., FREEDMAN, V. A., CORNMAN, J. C., WOLF, D. A. & MARCOTTE, J. E. 2005. Reconsidering substitution in long-term care: when does assistive technology take the place of personal care? *Journal of Gerontology*, 60B, S272-S280.
- AGREE, E. M., FREEDMAN, V. A. & SENGUPTA, M. 2004. Factors influencing the use of mobility technology in community-based long-term care. *Journal of Aging and Health*, 16, 267-307.
- AHLUWALIA, S. C., GILL, T. M., BAKER, D. I. & FRIED, T. R. 2010. Perspectives of older persons on bathing and bathing disability: a qualitative study. *Journal of the American Geriatrics Society*, 58, 450-456.
- AKERROYD, A. V. 1988. Ethnography, personal data and computers: the implications of data protection legislation for qualitative social research. In: FIELDING, N. G. & LEE, R. M. (eds.) *Using computers in qualitative research*. Greenwich, CT: SAGE Publications, Ltd.
- ALBERT, M. S. & BLACKER, D. 2006. Mild cognitive impairment and dementia. *Annual Review of Clinical Psychology*, 2, 379-388.
- ALEXOPOULOS, G. S., JESTE, D. V., CHUNG, H., CARPENTER, D., ROSS, R. & DOCHERTY, J. P. 2005. The expert consensus guideline series. Treatment of dementia and its behavioral disturbances. Introduction: methods, commentary, and summary. *Postgraduate Medicine*, Spec No., 6-22.
- ALLEN, S. M., FOSTER, A. & BERG, K. 2001. Receiving help at home: the interplay of human and technological assistance. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 56, S374-S382.

- ALSPAUGH, M. E. L., STEPHENS, M. A. P., TOWNSEND, A. L., ZARIT, S. H. & GREENE, R. 1999. Longitudinal patterns of risk for depression in dementia caregivers: objective and subjective primary stress as predictors. *Psychology & Aging*, 14, 34-43.
- ALTUS, D. E., ENGELMAN, K. K. & MATHEWS, R. M. 2002. Using family-style meals to increase participation and communication in persons with dementia. *Journal of Gerontological Nursing*, 28, 47-53.
- ALZHEIMER'S ASSOCIATION 2009. 2009 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 5, 234-270.
- ALZHEIMER'S RESEARCH UK 2015. Women and dementia: a marginalised minority. London: Alzheimer's Research UK.
- ALZHEIMER'S SOCIETY 2010. Paying care home fees. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2012. Dementia 2012: a national challenge. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2013a. Am I at risk of developing dementia? London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2013b. Communicating. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2013c. Dementia 2013: the hidden voice of loneliness. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2013d. Dressing. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2013e. Managing toilet problems and incontinence. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2013f. Rarer causes of dementia. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2013g. Washing and bathing. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2013h. What is Korsakoff's syndrome? London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2014a. Assessment and diagnosis. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2014b. Dementia 2014: Opportunity for Change. London: Alzheimer's Society.
- ALZHEIMER'S SOCIETY 2014c. Selecting a care home. London: Alzheimer's Society.
- AMELLA, E. J. 2002. Resistance at mealtimes for persons with dementia. *Journal of Nutrition, Health and Aging*, 6, 117-122.
- AMELLA, E. J., GRANT, A. P. & MULLOY, C. 2008. Eating behavior in persons with moderate to late-stage dementia: assessment and interventions. *Journal of the American Psychiatric Nurses Association*, 13, 360-367.
- AMINZADEH, F., DALZIEL, W. B., MOLNAR, F. J. & GARCIA, L. J. 2009. Symbolic meaning of relocation to a residential care facility for persons with dementia. *Aging & Mental Health*, 13, 487-496.
- AMINZADEH, F., DALZIEL, W. B., MOLNAR, F. J. & GARCIA, L. J. 2010. Meanings, functions, and experiences of living at home for individuals with dementia at the critical point of relocation. *Journal of Gerontological Nursing*, 36, 28-35.
- ANDERSON, S., ALLEN, P., PECKHAM, S. & GOODWIN, N. 2008. Asking the right questions: scoping studies in the commissioning of research on the organisation and delivery of health services. *Health Research Policy and Systems*, 6, 7-18.
- ANESHENSEL, C. S., PEARLIN, L. I. & SCHULER, R. H. 1993. Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behavior*, 34, 54-70.
- ARBER, S. & EVANDROU, M. 1993. Mapping the territory: ageing, independence and the life course. In: ARBER, S. & EVANDROU, M. (eds.) *Ageing, independence and the life course*. London: Jessica Kingsley Publishers.
- ARKSEY, H. & O'MALLEY, L. 2005. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8, 19-32.
- ARMSTRONG, N., NUGENT, C., MOORE, G. & FINLAY, D. 2010. Using smartphones to address the needs of persons with Alzheimer's disease. *Annals of telecommunications-Annales des télécommunications*, 65, 485-495.
- ARMSTRONG, R., HALL, B. J., DOYLE, J. & WATERS, E. 2011. 'Scoping the scope' of a cochrane review. *Journal of Public Health*, 33, 147-150.

- ASELAGE, M. 2010. Measuring mealtime difficulties: eating, feeding and meal behaviours in older adults with dementia. *Journal of Clinical Nursing*, 19, 621-631.
- ASELAGE, M. & AMELLA, E. 2010. An evolutionary analysis of mealtime difficulties in older adults with dementia. *Journal of Clinical Nursing*, 19, 33-41.
- ASELAGE, M., AMELLA, E. & WATSON, R. 2011. State of the science: alleviating mealtime difficulties in nursing home residents with dementia. *Nursing Outlook*, 59, 210-214.
- BAILEY, C. & SHEEHAN, C. 2009. Technology, older persons' perspectives and the anthropological ethnographic lens. *ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap*, 3, 96-109.
- BALOH, R. W., YUE, Q., SOCOTCH, T. M. & JACOBSON, K. M. 1995. White matter lesions and disequilibrium in older people: I. Case-control comparison. *Archives of Neurology*, 52, 970-974.
- BALTES, M. 1996. *The many faces of dependency*, New York, Cambridge University Press.
- BAMFORD, C. & BRUCE, E. 2000. Defining the outcomes of community care: the perspectives of older people with dementia and their carers. *Ageing & Society*, 20, 543-570.
- BARBAS, N. R. & WILDE, E. A. 2001. Competency issues in dementia: medical decision making, driving, and independent living. *Journal of Geriatric Psychiatry and Neurology*, 14, 199-212.
- BARBERGER-GATEAU, P., FABRIGOULE, C., AMIEVA, H., HELMER, C. & J.F., D. 2002. The disablement process: a conceptual framework for dementia-associated disability. *Dementia and Geriatric Cognitive Disorders*, 13, 60-66.
- BARRATT, J. A. 2004. Ensuring good nutrition in dementia care. *Reviews in Clinical Gerontology*, 14, 247-251.
- BARRETT, J. A. 1993. *Faecal incontinence and related problems in the older adult*, London, Edward Arnold.
- BARTLETT, R., GJERNES, T., LOTHERINGTON, A. T. & OBSTEFELDER, A. 2016. Gender, citizenship and dementia care: a scoping review of studies to inform policy and future research. *Health & social care in the community*.
- BARUCH, J., DOWNS, M., BALDWIN, C. & BRUCE, E. 2004. A case study in the use of technology to reassure and support a person with dementia. *Dementia*, 3, 371-392.
- BARZEL, U. S. 1991. Modern technology: a double-edged sword. *International Journal of Technology and Ageing*, 4, 89-92.
- BATE, A. 2017. Health and social care integration (England) (Briefing paper no. 7902). London: House of Commons Library.
- BATTY, D., BLAKE, M., BRIDGES, S., CRAWFORD, R., DEMAKAKOS, P., DE OLIVEIRA, C., HUSSEY, D., JACKOWSKA, M., JACKSON, S., MARMOT, M., MATTHEWS, K., NAZROO, J., OLDFIELD, Z., PHILO, D., SHANKAR, A., STEPTOE, A. & ZANINOTTO, P. 2014. The dynamics of ageing: evidence from the English Longitudinal Study of Ageing 2002-2012 (wave 6). The Institute for Fiscal Studies.
- BAXTER, P. & JACK, S. 2008. Qualitative case study methodology: study design and implementation for novice researchers. *The Qualitative Report*, 13, 544-559.
- BECK, C. 1988. Measurement of dressing performance in persons with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 3, 21-25.
- BECK, C., HEACOCK, P., MERCER, S. O., WALLS, R. C., RAPP, C. G. & VOGELPOHL, T. S. 1997. Improving dressing behavior in cognitively impaired nursing home residents. *Nursing Research*, 46, 126-132.
- BECK, C., HEACOCK, P., RAPP, C. G. & MERCER, S. O. 1993. Assisting cognitively impaired elders with activities of daily living. *American Journal of Alzheimer's Disease and Other Dementias*, 8, 11-20.
- BEHRMAN, S., CHOULIARAS, L. & EBMEIER, K. P. 2014. Considering the senses in the diagnosis and management of dementia. *Maturitas*, 77, 305-310.

- BELLEVILLE, S., CHERTKOW, H. & GAUTHIER, S. 2007. Working memory and control of attention in persons with Alzheimer's disease and mild cognitive impairment. *Neuropsychology*, 21, 459-469.
- BEN MORTENSON, W., OLIFFE, J. L., MILLER, W. C. & BACKMAN, C. L. 2012. Grey spaces: the wheeled fields of residential care. *Sociology of Health & Illness*, 34, 315-329.
- BENNETT, H. P., CORBETT, A. J., GADEN, S., GRAYSON, D. A., KRIL, J. J. & BROE, G. A. 2002. Subcortical vascular disease and functional decline: a 6-year predictor study. *Journal of the American Geriatrics Society*, 50, 1969-1977.
- BENTLEY, C., POWELL, L. A., ORRELL, A. & MOUNTAIN, G. A. 2014. Addressing design and suitability barriers to Telecare use: has anything changed? *Technology & Disability*, 26, 221-235.
- BERGEN, A. & WHILE, A. 2000. A case for case studies: exploring the use of case study design in community nursing research. *Journal of Advanced Nursing*, 31, 926-934.
- BERKHOUT, A., COOLS, H. & VAN HOUWELINGEN, H. 1998. The relationship between difficulties in feeding oneself and loss of weight in nursing-home patients with dementia. *Age and Ageing*, 27, 637-641.
- BEWERNITZ, M. W., MANN, W. C., DASLER, P. & BELCHIOR, P. 2009. Feasibility of machine-based prompting to assist persons with dementia. *Assistive Technology*, 21, 196-207.
- BHARUCHA, A. J., ANAND, V., FORLIZZI, J., DEW, M. A., REYNOLDS III, C. F., STEVENS, S. & WACTLAR, H. 2009. Intelligent assistive technology applications to dementia care: current capabilities, limitations, and future challenges. *The American Journal of Geriatric Psychiatry*, 17, 88-104.
- BHARUCHA, A. J., PANDAV, R., SHEN, C., DODGE, H. H. & GANGULI, M. 2004. Predictors of nursing facility admission: a 12-year epidemiological study in the United States. *Journal of the American Geriatrics Society*, 52, 434-439.
- BIGNELL, V. & GETLIFFE, K. 2001. Clinical guidelines for the promotion of continence in primary care: community nurses' knowledge, practice and perceptions of their role. *Primary Health Care Research & Development*, 2, 173-186.
- BJØRNEBY, S., TOPO, P., CAHILL, S., BEGLEY, E., JONES, K., HAGEN, I., MACIJAUSKIENE, J. & HOLTHE, T. 2004. Ethical considerations in the ENABLE Project. *Dementia*, 3, 297-312.
- BJØRNEBY, S., TOPO, P., HOLTHE, T. & RESEARCH, N. C. F. D. 1999. *Technology, ethics and dementia: A guidebook on how to apply technology in dementia care*, Norwegian Centre for Dementia Research.
- BLAKE, M., BRIDGES, S., HUSSEY, D. & MANDALIA, D. 2015. The dynamics of ageing: the 2010 English Longitudinal Study of Ageing (Wave 5) technical report. London: Institute of Fiscal Studies.
- BLOOD, I. 2013. A better life: valuing our later years. London: Joseph Rowntree Foundation.
- BOGER, J., HOEY, J., FENTON, K., CRAIG, T. & MIHAILIDIS, A. 2010. Using actors to develop technologies for older adults with dementia. A pilot study. *Gerontechnology*, 9, 450-463.
- BOGER, J., HOEY, J., POUPART, P., BOUTILIER, C., FERNIE, G. & MIHAILIDIS, A. 2006. A planning system based on Markov decision processes to guide people with dementia through Activities of Daily Living. *Transactions on Information Technology in Biomedicine*, 10, 323-333.
- BOGER, J. & MIHAILIDIS, A. 2011. The future of intelligent assistive technologies for cognition: devices under development to support independent living and aging-with-choice. *NeuroRehabilitation*, 28, 271-280.
- BOND, J. 1992. The medicalization of dementia. *Journal of Aging Studies*, 6, 397-403.
- BOND, J. & CABRERO, G. R. 2007. Health and dependency in later life. In: BOND, J., PEACE, S., DITTMANN-KOHLI, F. & WESTERHOF, G. (eds.) *Ageing in society: European perspectives on gerontology*. London: SAGE Publications, Ltd.
- BOND, S. & BOND, J. 1990. Outcomes of care within a multiple-case study in the evaluation of the Experimenta National Health Service nursing homes. *Age and Ageing*, 19, 11-18.

- BONNER, S. & IDRIS, T. 2012. Assistive technology as a means of supporting people with dementia: a review. London: Housing, Learning & Improvement Network (HLIN).
- BOSSSEN, A. L., KIM, H., WILLIAMS, K. N., STEINHOFF, A. E. & STRIEKER, M. 2015. Emerging roles for telemedicine and smart technologies in dementia care. *Smart Homecare Technology and Telehealth*, 3, 49-57.
- BOWLING, A. 2009. *Research methods in health: investigating health and health services*, New York, McGraw-Hill International.
- BOYLE, G. 2008. The Mental Capacity Act 2005: promoting the citizenship of people with dementia? *Health & Social Care in the Community*, 16, 529-537.
- BRANDT JR, E. N. & POPE, A. M. 1997. *Enabling America: assessing the role of rehabilitation science and engineering*, Washington, DC, National Academies Press.
- BRANFIELD, F. & BERESFORD, P. 2010. A better life: alternative approaches from a service user perspective. London: Joseph Rowntree Foundation.
- BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- BRAVO, C. V. 2004. Urinary and faecal incontinence and dementia. *Reviews in Clinical Gerontology*, 14, 129-136.
- BRIDGES, S., HUSSEY, D. & BLAKE, M. 2015. The dynamics of ageing: the 2012 English Longitudinal Study of Ageing (Wave 6) technical report. London: Institute of Fiscal Studies.
- BRINKMANN, S. & KVALE, S. 2005. Confronting the ethics of qualitative research. *Journal of Constructivist Psychology*, 18, 157-181.
- BRISENDEN, S. 1989a. A charter for personal care. *Progress*, 16, 6-8.
- BRISENDEN, S. 1989b. Young, gifted and disabled: entering the employment market. *Disability, Handicap & Society*, 4, 217-220.
- BRITISH MEDICAL ASSOCIATION 2001. *The medical profession and human rights: for a changing agenda*, London, Zed Books.
- BRITTAİN, K., CORNER, L., ROBINSON, L. & BOND, J. 2010. Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health & Illness*, 32, 272-287.
- BRITTAİN, K. R. & SHAW, C. 2007. The social consequences of living with and dealing with incontinence - a carers perspective. *Social Science & Medicine*, 65, 1274-1283.
- BRITTLE, N., LETT, K., LITTLECHILD, R. & SACKLEY, C. 2007. The disability profile of adults who receive adaptive equipment from local authority occupational therapy services. *The British Journal of Occupational Therapy*, 70, 479-482.
- BRODATY, H., GREEN, A. & LOW, L.-F. 2000. Caring for people with dementia: family carers for people with dementia. In: BURNS, A., O'BRIEN, J. & AMES, D. (eds.) *Dementia*. USA: Taylor & Francis Group.
- BRODATY, H., THOMSON, C., THOMPSON, C. & FINE, M. 2005. Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, 20, 537-546.
- BROOKER, D. 2003. What is person-centred care in dementia? *Reviews in Clinical Gerontology*, 13, 215-222.
- BROOKS, L. & LOEWENSTEIN, D. 2010. Assessing the progression of mild cognitive impairment to Alzheimer's disease: current trends and future directions. *Alzheimer's Research & Therapy*, 2, 28.
- BROWN, S., HINE, N., SIXSMITH, A. & GARNER, P. 2004. Care in the community. *BT Technology Journal*, 22, 56-64.
- BRUMMEL-SMITH, K. & DANGIOLO, M. 2009. Assistive technologies in the home. *Clinics in Geriatric Medicine*, 25, 61-77.

- BUCHMAN, A. S., WILSON, R. S., BOYLE, P. A., BIENIAS, J. L. & BENNETT, D. A. 2007. Grip strength and the risk of incident Alzheimer's Disease. *Neuroepidemiology*, 29, 66-73.
- BURKE, S. 2010. A better life: alternative approaches from the perspective of families and carers of older people with high support needs. London: Joseph Rowntree Foundation.
- BURNS, R. B. 2000. *Introduction to research methods*, London, SAGE Publications, Ltd.
- CAHILL, S., BEGLEY, E., TOPO, P., SAARIKALLE, K., MACIJAUŠKIENE, J., BUDRAITIENE, A., HAGEN, I., HOLTHE, T. & JONES, K. 2004. 'I know where this is going and I know it won't go back'. *Dementia*, 3, 313-330.
- CAHILL, S., MACIJAUŠKIENE, J., NYGÅRD, A.-M., FAULKNER, J.-P. & HAGEN, I. 2007. Technology in dementia care. *Technology and Disability*, 19, 55-60.
- CALKINS, M. P. & NAMAZI, K. H. 1991. Caregivers' perceptions of the effectiveness of home modifications for community living adults with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 6, 25-29.
- CAMICOLI, R., MOORE, M. M., SEXTON, G., HOWIESON, D. B. & KAYE, J. A. 1999. Age-related brain changes associated with motor function in healthy older people. *Journal of the American Geriatrics Society*, 47, 330-4.
- CAMPBELL-SMITH, C. 2007. Ethics and primary health care. In: LEATHARD, A. & MCLAREN, S. (eds.) *Ethics: contemporary challenges in health and social care*. Bristol, UK: The Policy Press.
- CANTLEY, C. & WILSON, R. C. 2002. 'Put yourself in my place': designing and managing care homes for people with dementia. Joseph Rowntree Foundation.
- CANTOR, M. H. 1975. Neighbors and friends: an overlooked resource in the informal support system. *Research on Aging*, 1, 434-463.
- CARE QUALITY COMMISSION 2011. The state of health care and adult social care in England: An overview of key themes in care in 2010/11. London: Care Quality Commission.
- CARERS UK. 2014. *Direct payments* [Online]. Available: <http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments>.
- CARON, C. D., DUCHARME, F. & GRIFFITH, J. 2006. Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. *Canadian Journal on Aging/Revue canadienne du vieillissement*, 25, 193-205.
- CARON, C. D., GRIFFITH, J. & ARCAND, M. 2005. End-of-life decision making in dementia. *Dementia*, 4, 113-136.
- CARRILLO, M. C., DISHMAN, E. & PLOWMAN, T. 2009. Everyday technologies for Alzheimer's disease care: research findings, directions, and challenges. *Alzheimer's and Dementia*, 5, 479-488.
- CARSWELL, W., MCCULLAGH, P. J., AUGUSTO, J. C., MARTIN, S., MULVENNA, M. D., ZHENG, H., WANG, H. Y., WALLACE, J. G., MCSORLEY, K., TAYLOR, B. & JEFFERS, W. P. 2009. A review of the role of assistive technology for people with dementia in the hours of darkness. *Technology and Health Care*, 17, 281-304.
- CASH, M. 2003. Assistive technology and people with dementia. *Reviews in Clinical Gerontology*, 13, 313-319.
- CAVANAUGH, J. C. & KINNEY, J. M. 1998. Accuracy of caregivers' recollections of caregiving hassles. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 53B, P40-P42.
- CHAI, J., CHU, F. C., CHOW, T. W., SHUM, N. C. & HUI, W. W. 2006. Influence of dental status on nutritional status of geriatric patients in a convalescent and rehabilitation hospital. *International Journal of Prosthodontics*, 19, 244-249.
- CHALLIS, D., WEINER, K., DARTON, R., HUGHES, J. & STEWART, K. 2001. Emerging patterns of care management: arrangements for older people in England. *Social Policy & Administration*, 35, 672-687.

- CHALMERS, J. M., LEVY, S. M., BUCKWALTER, K. C., ETTINGER, R. L. & KAMBHU, P. P. 1996. Factors influencing nurses' aides provision of oral care for nursing facility residents. *Special Care in Dentistry*, 16, 71-79.
- CHANG, C. & ROBERTS, B. 2008. Feeding difficulty in older adults with dementia. *Journal of Clinical Nursing*, 17, 2266-2274.
- CHEEK, P., NIKPOUR, L. & NOWLIN, H. D. 2005. Aging well with smart technology. *Nursing Administration Quarterly*, 29, 329-338.
- CHEN, J., KAM, A. H., ZHANG, J., LIU, N. & SHUE, L. 2005. Bathroom activity monitoring based on sound. *Proceedings of the third international conference on pervasive computing*. Munich, Germany: Springer-Verlag.
- CHERTKOW, H. 2008. Diagnosis and treatment of dementia: introduction. *Canadian Medical Association Journal*, 178, 316-321.
- CHESHIRE, H., HUSSEY, D., MEDINA, J., PICKERING, K., WOOD, N., WARD, K., TAYLOR, K. & LESSOF, C. 2012. Financial circumstances, health and well-being of the older population in England: the 2008 English Longitudinal Study of Ageing technical report. London: Institute of Fiscal Studies.
- CLARKE, P., CHAN, P., SANTAGUIDA, P. L. & COLANTONIO, A. 2009. The use of mobility devices among institutionalized older adults. *Journal of Aging and Health*, 21, 611-626.
- CLOUGH, R., MANTHORPE, J., OLDER PEOPLE RESEARCHING SOCIAL ISSUES, RAYMOND, V., SUMNER, K., BRIGHT, L. & HAY, J. 2007. The support older people want and the services they need. London: Joseph Rowntree Foundation.
- CLOUTIER, H. D., J. PREVOST, C. TEIGER, E. 1999. Importance of experience for older home care workers in facing up to the constraints of work. *Experimental Aging Research*, 25, 405-410.
- COCKRELL, J. R. & FOLSTEIN, M. 2002. Mini-Mental State Examination. In: COPELAND, J. R. M., ABOU-SALEH, M. T. & BLAZER, D. G. (eds.) *Principles and Practice of Geriatric Psychiatry*. 2 ed. West Sussex: John Wiley and Sons Ltd.
- COEHLO, D. P., HOOKER, K. & BOWMAN, S. 2007. Institutional placement of persons with dementia - what predicts occurrence and timing? *Journal of Family Nursing*, 13, 253-277.
- COHEN-MANSFIELD, J. & WIRTZ, P. W. 2009. The reasons for nursing home entry in an adult day care population: caregiver reports versus regression results. *Journal of Geriatric Psychiatry and Neurology*, 22, 274-281.
- COLEMAN, P. & WATSON, N. M. 2006. Oral care provided by certified nursing assistants in nursing homes. *Journal of the American Geriatrics Society*, 54, 138-143.
- COMAS-HERRERA, A., NORTHEY, S., WITTENBERG, R., KNAPP, M., BHATTACHARYYA, S. & BURNS, A. 2011. Future costs of dementia-related long-term care: exploring future scenarios. *International Psychogeriatrics*, 23, 20-30.
- COMAS-HERRERA, A., WITTENBERG, R., GORI, C., COSTA-I-FONT, J., DI MAIO, A., PATXOT, C., PICKARD, L., POZZI, A. & ROTHGANG, H. 2006. Future long-term care expenditure in Germany, Spain, Italy and the United Kingdom. *Ageing & Society*, 26, 285-302.
- COMAS-HERRERA, A., WITTENBERG, R., PICKARD, L. & KNAPP, M. 2007. Cognitive impairment in older people: future demand for long-term care services and the associated costs. *International Journal of Geriatric Psychiatry*, 22, 1037-1045.
- COMMUNITIES AND LOCAL GOVERNMENT 2013. Disabled facilities grant. London: Department for Communities and Local Government and the Welsh Assembly Government.
- CONNELL, C. M. & GIBSON, G. D. 1997. Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist*, 37, 355-364.
- CONNOLLY, M. J. & WILSON, A. S. 1990. Feeding aids. *British Medical Journal*, 301, 378-379.
- COPPOLA, L., CASERTA, F., GRASSIA, A., MASTROLORENZO, L., ALTRUI, L., TONDI, G., VERDE, S. & COPPOLA, A. 2002. Urinary incontinence in the elderly: relation to cognitive and motor function. *Archives of Gerontology and Geriatrics*, 35, 27-34.

- CORCORAN, M. & GITLIN, L. N. 1991. Environmental influences on behavior of the elderly with dementia: principles for intervention in the home. *Physical & Occupational Therapy in Geriatrics*, 9, 5-22.
- COTTER, E. M., BURGIO, L. D., ROTH, D. L., GERSTLE, J. & RICHARDSON, P. 2008. Comparison of caregiver and Occupational Therapist ratings of dementia patients' performance of Activities of Daily Living. *Journal of Applied Gerontology*, 27, 215-225.
- COURTNEY, K. L., DEMIRIS, G. & HENSEL, B. K. 2007. Obtrusiveness of information-based assistive technologies as perceived by older adults in residential care facilities: a secondary analysis. *Medical Informatics and the Internet in Medicine*, 32, 241-249.
- COWAN, D. & TURNER-SMITH, A. 1999. The role of assistive technology in alternative models of care for older people,. *Royal Commission on Long-Term Care*. London: Stationery Office.
- COYNE, M. L. & HOSKINS, L. 1997. Improving eating behaviors in dementia using behavioral strategies. *Clinical Nursing Research*, 6, 275-290.
- CRISP, J. 1999. Towards a partnership in maintaining personhood. In: ADAMS, T. & CLARKE, C. (eds.) *Dementia care: developing partnerships in practice*. London: Bailliere Tindall.
- CROGAN, N. L., SHULTZ, J. A., ADAMS, C. E. & MASSEY, L. K. 2001. Barriers to nutrition care for nursing home residents. *Journal of Gerontological Nursing*, 27, 25-31.
- CROWE, V. 2003. Eating and swallowing difficulties. In: MARSHALL, M. (ed.) *Food glorious food: perspectives on food and dementia*. London: Hawker Publications Ltd.
- DARK, J. & SANDER, R. 2014. An overview of communication, movement and perception difficulties after stroke. *Nursing Older People*, 26, 32-37.
- DAVIES, R. J., NUGENT, C. D., DONNELLY, M. P., HETTINGA, M., MEILAND, F. J., MOELAERT, F., MULVENNA, M. D., BENGTSOON, J. E., CRAIG, D. & DROES, R. M. 2009. A user driven approach to develop a cognitive prosthetic to address the unmet needs of people with mild dementia. *Pervasive and Mobile Computing*, 5, 253-267.
- DAVIES, S., ELLIS, L. & LAKER, S. 2000. Promoting autonomy and independence for older people within nursing practice: an observational study. *Journal of Clinical Nursing*, 9, 127-136.
- DAVIES, S., GOODMAN, C., BUNN, F., VICTOR, C., DICKINSON, A., ILIFFE, S., GAGE, H., MARTIN, W. & FROGGATT, K. 2011. A systematic review of integrated working between care homes and health care services. *BMC Health Services Research*, 11, 320.
- DAVIES, S. & NOLAN, M. 2006. 'Making it better': self-perceived roles of family caregivers of older people living in care homes: a qualitative study. *International Journal of Nursing Studies*, 43, 281-291.
- DAY, K., CARREON, D. & STUMP, C. 2000. The therapeutic design of environments for people with dementia: a review of the empirical research. *The Gerontologist*, 40, 397-416.
- DE VREESE, L. P., CAFFARRA, P., SAVARÈ, R., CERUTTI, R., FRANCESCHI, M. & GROSSI, E. 2008. Functional disability in early Alzheimer's disease – a validation study of the Italian version of the Disability Assessment for Dementia Scale. *Dementia and Geriatric Cognitive Disorders*, 25, 186-194.
- DE VUGT, M. E., STEVENS, F., AALTEN, P., LOUSBERG, R., JASPERS, N. & VERHEY, F. R. J. 2005. A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *International Psychogeriatrics*, 17, 577-589.
- DELLASEGA, C. & NOLAN, M. 1997. Admission to care: facilitating role transition amongst family carers. *Journal of Clinical Nursing*, 6, 443-451.
- DEMIRIS, G. & HENSEL, B. 2009. "Smart homes" for patients at the end of life. *Journal of Housing for the Elderly*, 23, 106-115.
- DENNEHY, C. 2006. Analysis of patients' rights: dementia and PEG insertion. *British Journal of Nursing*, 15, 18-20.
- DENSCOMBE, M. 2010. *The good research guide: for small-scale social research projects*, Buckingham, Open University Press.

- DEPARTMENT FOR WORK AND PENSIONS 2015. Proposed benefit and pension rates 2016 to 2017. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/480317/proposed_benefit_and_pension_rates_2016_to_2017.pdf: Department for Work and Pensions.
- DEPARTMENT OF HEALTH 1992. The nutrition of elderly people. London: Department of Health.
- DEPARTMENT OF HEALTH 2001. National Service Framework for Older People. London: Department of Health.
- DEPARTMENT OF HEALTH 2006. Our health, our care, our say: A new direction for communitiy services. London: Department of Health.
- DEPARTMENT OF HEALTH 2008. Transforming the quality of care: consultation on a National Dementia Strategy. London: Department of Health.
- DEPARTMENT OF HEALTH 2009. Living well with dementia: a National Dementia Strategy. London: Department of Health.
- DEPARTMENT OF HEALTH 2011. Research and development work relating to assistive technology 2010-11. London: Department of Health.
- DEPARTMENT OF HEALTH 2012a. Caring for our future: reforming care and support. London: Department of Health.
- DEPARTMENT OF HEALTH 2012b. A concordat between the Department of Health and the telehealth and telecare industry. London: Department of Health.
- DEPARTMENT OF HEALTH 2012c. Prime Minister's challenge on dementia. London: The Stationery Office.
- DEPARTMENT OF HEALTH 2012d. Prime Minister's challenge on dementia: delivering major improvements in dementia care and research by 2015. London: Department of Health.
- DEPARTMENT OF HEALTH 2013a. Draft national minimum eligibility threshold for adult care and support: a discussion document. London: Department of Health.
- DEPARTMENT OF HEALTH 2013b. The Prime Minister's challenge on dementia: annual report of progress. London: Department of Health.
- DEPARTMENT OF HEALTH 2015. Prime Minister's challenge on dementia 2020. London: Department of Health.
- DEVINS, G. M. & ORME, C. M. 1985. Center for Epidemiologic Studies Depression Scale. *Test Critiques*, 2, 144-60.
- DEWING, J. 2002. From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, 1, 157-171.
- DIERCKX, E., ENGELBORGH, S., DE RAEDT, R., DE DEYN, P. P. & PONJAERT-KRISTOFFERSEN, I. 2007. Differentiation between mild cognitive impairment, Alzheimer's disease and depression by means of cued recall. *Psychological Medicine*, 37, 747-755.
- DILNOT, A., WARNER, N. & WILLIAMS, J. 2011. Fairer care funding: the report of the Commission on Funding of Care and Support. London: Department of Health.
- DOBSON, C. & MENTAL CAPACITY ACT WORKING PARTY 2008. *Conducting research with people not having the capacity to consent to their participation: A practical guide for researchers*, British Psychological Society, Professional Practice Board.
- DONINI, L. M., SAVINA, C. & CANNELLA, C. 2003. Eating habits and appetite control in the elderly: the anorexia of aging. *International Psychogeriatrics*, 15, 73-87.
- DORIN, L., KRUPA, E., METZING, S. & BÜSCHER, A. 2016. Gender disparities in German home-care arrangements. *Scandinavian Journal of Caring Sciences*, 30, 164-174.
- DORNAER, B. 2005. Nutrition for the dementia resident. *Nursing Homes and Senior Citizen Care*, 54, 29-30.
- DOWNS, M. 2000. Dementia in a socio-cultural context: an idea whose time has come. *Ageing and Society*, 20, 369-375.

- DOWNS, M. 2013a. Embodiment: the implications for living well with dementia. *Dementia*, 12, 368-374.
- DOWNS, M. 2013b. Putting people - and compassion - first: the United Kingdom's approach to person-centered care for individuals with dementia. *Generations*, 37, 53-59.
- DRAME, M., FIEROBE, F., LANG, P.-O., JOLLY, D., BOYER, F., MAHMOUDI, R., SOMME, D., LANIECE, I., HEITZ, D., GAUVIN, J.-B., VOISIN, T., DE WAZIERES, B., GONTHEIR, R., ANKRI, J., SAINT-JEAN, O., COUTURIER, P., JEANDEL, C., BLANCHARD, F. & NOVELLA, J.-L. 2011. Predictors of institution admission in the year following acute hospitalisation of elderly people. *The Journal of Nutrition, Health and Aging*, 15, 399-403.
- DRENNAN, V., COLE, L. & ILIFFE, S. 2011. A taboo within a stigma? A qualitative study of managing incontinence with people with dementia living at home. *BMC Geriatrics*, 11, 75.
- DUFF, K., MCCAFFREY, R. J. & SOLOMON, G. S. 2002. The Pocket Smell Test: discriminating probable Alzheimer's disease from vascular dementia and major depression. *Journal of Neuropsychiatry and Clinical Neuroscience*, 14, 197-201.
- DUFFY, L. M. 1987. Managing urinary incontinence in persons with Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 2, 13-19.
- DUNLOP, D., MANHEIM, L. M., SOHN, M., LIU, X. & CHANG, R. W. 2002. Incidence of functional limitation in older adults: the impact of gender, race, and chronic conditions. *Archives of Physical Medicine and Rehabilitation*, 83, 964-971.
- DUNN, J. C., THIRU-CHELVAM, B. & BECK, C. H. 2002. Bathing. Pleasure or pain? *Journal of Gerontological Nursing*, 28, 6-13.
- DURNBAUGH, T., HALEY, B. & ROBERTS, S. 1996. Assessing problem feeding behaviors in mid-stage Alzheimer's disease. *Geriatric Nursing*, 17, 63-67.
- DYCK, I., KONTOS, P., ANGUS, J. & MCKEEVER, P. 2005. The home as a site for long-term care: meanings and management of bodies and spaces. *Health & Place*, 11, 173-185.
- EASTERLING, C. & ROBBINS, E. 2008. Dementia and dysphagia. *Geriatric Nursing*, 29, 275-285.
- EDELMAN, P., KUHN, D. & FULTON, B. 2004. Influence of cognitive impairment, functional impairment and care setting on dementia care mapping results. *Aging & Mental Health*, 8, 514-523.
- EDLUND, C. & BJÖRKLUND, A. 2011. Family caregivers' conceptions of usage of and information on products, technology and Web-based services. *Technology & Disability*, 23, 205-214.
- EJAZ, F. K., NOELKER, L. S., SCHUR, D., WHITLATCH, C. J. & LOOMAN, W. J. 2002. Family satisfaction with nursing home care for relatives with dementia. *Journal of Applied Gerontology*, 21, 368-384.
- ENGEL, S. E., KIELY, D. K. & MITCHELL, S. L. 2006. Satisfaction with end-of-life care for nursing home residents with advanced dementia. *Journal of the American Geriatrics Society*, 54, 1567-1572.
- ESRC. 2012. *ESRC Framework for Research Ethics (FRE) 2010 updated September 2012* [Online]. <http://www.esrc.ac.uk/about-esrc/information/framework-for-research-ethics/index.aspx>.
- ESTES, C. L. & SWAN, J. H. 1992. *The long-term care crisis: elders trapped in the no-care zone*, Newbury Park, California, SAGE Publications, Ltd.
- EVANS, D. 2007. The use of disposable pull-up pants in continence management. *Continence UK*, 1, 72-73.
- FADER, M., COTTENDEN, A. M. & GETLIFFE, K. 2008. Absorbent products for moderate-heavy urinary and/or faecal incontinence in women and men. *Cochrane Database of Systematic Reviews*.
- FAULKNER, M. 2001. Empowerment, disempowerment and the care of older people. *Nursing Older People*, 13, 18-20.
- FERRARA, M., LANGIANO, E., DI BRANGO, T., DI CIOCCIO, L., BAUCO, C. & DE VITO, E. 2008. Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health and Quality of Life Outcomes*, 6, 93-97.

- FEYEREISEN, P. 1999. Disorders of everyday actions in subjects suffering from senile dementia of Alzheimer's type: an analysis of dressing performance. *Neuropsychological Rehabilitation*, 9, 169-188.
- FINE, M. & GLENDINNING, C. 2005. Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing & Society*, 25, 601-621.
- FINUCANE, T. E., CHRISTMAS, C. & TRAVIS, K. 1999. Tube feeding in patients with advanced dementia: a review of evidence. *JAMA: Journal of the American Medical Association*, 282, 1365-1370.
- FLEMING, R. & SUM, S. 2014. Empirical studies on the effectiveness of assistive technology in the care of people with dementia: a systematic review. *Journal of Assistive Technologies*, 8, 14-34.
- FLICK, U. 2014. *An introduction to qualitative research*, London, SAGE Publications, Ltd.
- FOLSTEIN, M., FOLSTEIN, S. & MCHUGH, P. 1975. Mini-Mental State: a practical method for grading the cognitive status of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.
- FORBES, D. A., JANSEN, S. L., MARKLE-REID, M., HAWRANIK, P., MORGAN, D., HENDERSON, S., LEIPERT, B., PEACOCK, S. & KINGSTON, D. 2008. Gender differences in use and availability of home and community-based services for people with dementia. *Canadian Journal of Nursing Research*, 40, 38-59.
- FORLIZZI, J., DISALVO, C. & GEMPERLE, F. 2004. Assistive robotics and an ecology of elders living independently in their homes. *Human-Computer Interaction*, 19, 25-59.
- FOSSEY, J., BALLARD, C., JUSZCZAK, E., JAMES, I., ALDER, N., JACOBY, R. & HOWARD, R. 2006. Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *British Medical Journal*, 332, 756-761.
- FOX, P. L. 1995. Rehabilitation in practice: environmental modifications in the homes of elderly Canadians with disabilities. *Disability & Rehabilitation*, 17, 43-49.
- FOY, S. S. & MITCHELL, M. M. 1991. Factors contributing to learned helplessness in the institutionalized aged: a literature review. *Physical & Occupational Therapy in Geriatrics*, 9, 1-23.
- FREEDMAN, V. A. 1996. Family structure and the risk of nursing home admission. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 51, S61-S69.
- FRENCH, S. 1998. What's so great about independence? In: SWAIN, J., FINKELSTEIN, V., FRENCH, S. & OLIVER, M. (eds.) *Disabling barriers - enabling environments*. London: SAGE Publications, Ltd.
- GALE, C. R., COOPER, C. & SAYER, A. A. 2015. Prevalence of frailty and disability: findings from the English Longitudinal Study of Ageing. *Age and Ageing*, 44, 162-165.
- GALLAGHER, D., MHAOLAIN, A. N., CROSBY, L., RYAN, D., LACEY, L., COEN, R. F., WALSH, C., COAKLEY, D., WALSH, J. B., CUNNINGHAM, C. & LAWLOR, B. A. 2011. Determinants of the desire to institutionalize in Alzheimer's caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 26, 205-211.
- GANNON, B. & NOLAN, B. 2007. The impact of disability transitions on social inclusion. *Social Science & Medicine*, 64, 1425-1437.
- GARWOOD, S. 2010. A better life for older people with high support needs in housing with care. London: Joseph Rowntree Foundation.
- GAUGLER, J., DUVAL, S., ANDERSON, K. & KANE, R. 2007. Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatrics*, 7, 13.
- GAUGLER, J., MITTELMAN, M. S., HEPBURN, K. & NEWCOMER, R. 2009a. Predictors of change in caregiver burden and depressive symptoms following nursing home admission. *Psychology & Aging*, 24, 385-396.
- GAUGLER, J. E. 2005. Family involvement in residential long-term care: a synthesis and critical review. *Ageing & Mental Health*, 9, 105-118.

- GAUGLER, J. E., ANDERSON, K. A. & LEACH, C. R. 2004. Predictors of family involvement in residential long-term care. *Journal of Gerontological Social Work*, 42, 3-26.
- GAUGLER, J. E., EDWARDS, A. B., FEMIA, E. E., ZARIT, S. H., STEPHENS, M. A. P., TOWNSEND, A. & GREENE, R. 2000. Predictors of institutionalization of cognitively impaired elders: family help and the timing of placement. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 55, P247-P255.
- GAUGLER, J. E., KANE, R. L., KANE, R. A., CLAY, T. & NEWCOMER, R. 2003. Caregiving and institutionalization of cognitively impaired older people: utilizing dynamic predictors of change. *Gerontologist*, 43, 219-229.
- GAUGLER, J. E., KANE, R. L., KANE, R. A., CLAY, T. & NEWCOMER, R. 2005. Modeling time to institutionalization in dementia. *Research and Practice in Alzheimer's Disease*, 10, 185-193.
- GAUGLER, J. E., YU, F., KRICHBAUM, K. & WYMAN, J. F. 2009b. Predictors of nursing home admission for persons with dementia. *Medical Care*, 47, 191-198.
- GIBSON, G., DICKINSON, C., BRITTAI, K. & ROBINSON, L. 2015. The everyday use of assistive technology by people with dementia and their family carers: a qualitative study. *BMC Geriatrics*, 15, 1-10.
- GIBSON, G., NEWTON, L., PRITCHARD, G., FINCH, T., BRITTAI, K. & ROBINSON, L. 2014. The provision of assistive technology products and services for people with dementia in the United Kingdom. *Dementia*, 0, 1-21.
- GIGNAC, M. A. & COTT, C. 1998. A conceptual model of independence and dependence for adults with chronic physical illness and disability. *Social Science & Medicine*, 47, 739-753.
- GILL, T. M., HAN, L. & ALLORE, H. G. 2007. Bath aids and the subsequent development of bathing disability among community-living older persons. *Journal of the American Geriatrics Society*, 55, 1757-1763.
- GILLETTE-GUYONNET, S., ANDRIEU, S., NOURHASHEMI, F., GARDETTE, V., COLEY, N., CANTET, C., GAUTHIER, S., OUSSET, P.-J. & VELLAS, B. 2011. Long-term progression of Alzheimer's disease in patients under antidementia drugs. *Alzheimer's and Dementia*, 7, 579-592.
- GILLIOZ, A. S., VILLARS, H., VOISIN, T., CORTES, F., GILLETTE-GUYONNET, S., ANDRIEU, S., GARDETTE, V., NOURHASHÉMI, F., OUSSET, P. J., JOUANNY, P. & VELLAS, B. 2009. Spared and impaired abilities in community-dwelling patients entering the severe stage of Alzheimer's Disease. *Dementia and Geriatric Cognitive Disorders*, 28, 427-432.
- GIOVANNETTI, T., BETTCHER, B. M., BRENNAN, L., LIBON, D., KESSLER, R. & DUEY, K. 2008. Coffee with jelly or un buttered toast: commissions and omissions are dissociable aspects of everyday action impairment in Alzheimer's disease. *Neuropsychology*, 22, 235-245.
- GITLIN, L. N. 2003. Conducting research on home environments: lessons learned and new directions. *The Gerontologist*, 43, 628-637.
- GITLIN, L. N., MILLER, K. S. & BOYCE, A. 1999. Bathroom modifications for frail elderly renters: outcomes of a community-based program. *Technology & Disability*, 10, 141-149.
- GITLIN, L. N., WINTER, L., DENNIS, M. P., CORCORAN, M., SCHINFELD, S. & HAUCK, W. W. 2002. Strategies used by families to simplify tasks for individuals with Alzheimer's disease and related disorders. *The Gerontologist*, 42, 61-69.
- GODWIN, B. 2012. The ethical evaluation of assistive technology for practitioners: a checklist arising from a participatory study with people with dementia, family and professionals. *Journal of Assistive Technologies*, 6, 123-135.
- GOLANT, S. M. 2003. Conceptualizing time and behavior in environmental gerontology: a pair of old issues deserving new thought. *The Gerontologist*, 43, 638-648.
- GOV.UK. 2015. *Disabled Facilities Grants* [Online]. Available: <https://www.gov.uk/disabled-facilities-grants/what-youll-get>.
- GOVERNMENT OFFICE FOR SCIENCE & FORESIGHT 2016. Future of an ageing population. London: Government Office for Science.

- GRAESSEL, E., LUTTENBERGER, K., BLEICH, S., ADABBO, R. & DONATH, C. 2011. Home nursing and home help for dementia patients: predictors for utilization and expected quality from a family caregiver's point of view. *Archives of Gerontology and Geriatrics*, 52, 233-238.
- GREENHALGH, T., PROCTER, R., WHERTON, J., SUGARHOOD, P. & SHAW, S. 2012. The organising vision for telehealth and telecare: discourse analysis. *BMJ Open*, 2, e001574.
- GREENWALD, B. S., KRAMER-GINSBERG, E., MARIN, D. B., LAITMAN, L. B., HERMANN, C. K., MOHS, R. C. & DAVIS, K. L. 1989. Dementia with coexistent major depression. *American Journal of Psychiatry*, 146, 1472-1478.
- GRIFFIN, R. L. 1995. Factors contributing to minimizing weight loss in patients with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 10, 33-36.
- GRISSE, T., APPELBAUM, P. S. & HILL-FOTOUHI, C. 1997. The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. *Psychiatric Services*, 48, 1415-1419.
- GRUNDY, E. & JITLAL, M. 2007. Socio-demographic variations in moves to institutional care 1991–2001: a record linkage study from England and Wales. *Age and Ageing*, 36, 424-430.
- HABERMANN, S., COOPER, C., KATONA, C. & LIVINGSTON, G. 2009. Predictors of entering 24-hour care for people with Alzheimer's disease: results from the LASER-AD study. *International Journal of Geriatric Psychiatry*, 24, 1291-1298.
- HAGEN, I., HOLTHE, T., GILLIARD, J., TOPO, P., CAHILL, S., BEGLEY, E., JONES, K., DUFF, P., MACIJAUSKIENE, J., BUDRAITIENE, A., BJØRNEBY, S. & ENGEDAL, K. 2004. Development of a protocol for the assessment of assistive aids for people with dementia. *Dementia*, 3, 281-296.
- HÄGGBLÖM-KRONLÖF, G. & SONN, U. 2007. Use of assistive devices – a reality full of contradictions in elderly persons' everyday life. *Disability and Rehabilitation: Assistive Technology*, 2, 335-345.
- HÄGGLUND, D. 2010. A systematic literature review of incontinence care for persons with dementia: the research evidence. *Journal of Clinical Nursing*, 19, 303-312.
- HANSON, L. C., ERSEK, M., GILLIAM, R. & CAREY, T. S. 2011. Oral feeding options for people with dementia: a systematic review. *Journal of the American Geriatrics Society*, 59, 463-472.
- HARDY, B., YOUNG, R. & WISTOW, G. 1999. Dimensions of choice in the assessment and care management process: the views of older people, carers and care managers. *Health & Social Care in the Community*, 7, 483-491.
- HARDY, S. & GROGAN, S. 2009. Preventing disability through exercise: investigating older adults' influences and motivations to engage in physical activity. *Journal of Health Psychology*, 14, 1036-1046.
- HARGREAVES, T. 2008. Nutritional issues for people with dementia. *Nursing & Residential Care*, 10, 118-122.
- HAWRANIK, P. G. 1998. The role of cognitive status in the use of inhome services: implications for nursing assessment. *Canadian Journal of Nursing Research*, 30, 45-65.
- HAWRANIK, P. G. & STRAIN, L. A. 2001. Cognitive impairment, disruptive behaviors, and home care utilization. *Western Journal of Nursing Research*, 23, 148-162.
- HAYASHI, M. 2013. *The care of older people: England and Japan, a comparative study*, London, UK, Pickering & Chatto.
- HEALTH AND SAFETY EXECUTIVE 2014. Managing offensive/hygiene waste safely. Norwich, UK: The Stationery Office.
- HELVIK, A.-S., ENGEDAL, K., BENTH, J. Š. & SELBÆK, G. 2014. A 52 month follow-up of functional decline in nursing home residents – degree of dementia contributes. *BMC Geriatrics*, 14, 45.
- HENDRIE, H. C. 1998. Epidemiology of dementia and Alzheimer's Disease. *American Journal of Geriatric Psychiatry*, 6, S3-S18.
- HERRIOTT, R. E. & FIRESTONE, W. A. 1983. Multisite qualitative policy research: optimizing description and generalizability. *Educational Researcher*, 12, 14-19.

- HIRST, M. 2005. Carer distress: a prospective, population-based study. *Social Science & Medicine*, 61, 697-708.
- HM TREASURY 2015. Spending Review and Autumn Statement 2015. England: HM Treasury.
- HOENIG, H., TAYLOR, D. H. J. & SLOAN, F. A. 2003. Does assistive technology substitute for personal assistance among the disabled elderly? *American Journal of Public Health*, 93, 330-337.
- HOLSINGER, T., DEVEAU, J., BOUSTANI, M. & WILLIAMS, J. W. 2007. Does this patient have dementia? *JAMA: Journal of the American Medical Association*, 297, 2391-2404.
- HOMER, J., ALBERTS, M. J., DAWSON, D. V. & COOK, G. M. 1994. Swallowing in Alzheimer's disease. *Alzheimer Disease & Associated Disorders*, 8, 177-189.
- HONG, S.-I., HASCHE, L. & LEE, M. J. 2011. Service use barriers differentiating care-givers' service use patterns. *Ageing and Society*, 31, 1307-1329.
- HORGAS, A. L. & ABOWD, G. 2004. The impact of technology on living environments. In: PEW, R. W. & VAN HEMEL, S. B. (eds.) *Technology for adaptive ageing*. Washington, DC: The National Academies Press.
- HOSMER JR, D. W. & LEMESHOW, S. 2004. *Applied logistic regression*, London, John Wiley & Sons.
- HOTOPF, M. 2005. The assessment of mental capacity. *Clinical Medicine*, 5, 580-584.
- HUGHES, C. P., BERG, L., DANZIGER, W. L., COBEN, L. A. & MARTIN, R. L. 1982. A new clinical scale for the staging of dementia. *The British Journal of Psychiatry*, 140, 566-572.
- HUMPHRIES, R., FORDER, J. & FERNÁNDEZ, J.-L. 2010. Securing good care for more people: options for reform. London: The King's Fund.
- HUTCHINSON, S. A. 1990. The case study approach. In: MOODY, L. E. (ed.) *Advancing nursing science through research*. Newbury Park, California: SAGE Publications, Ltd.
- ILTANEN-TÄHKÄVUORI, S., WIKBERG, M. & TOPO, P. 2012. Design and dementia: a case of garments designed to prevent undressing. *Dementia*, 11, 49-59.
- INNES, A. 2009. Dementia studies: a social science perspective. London: SAGE Publications, Ltd.
- INNES, A. & MANTHORPE, J. 2012. Developing theoretical understandings of dementia and their application to dementia care policy in the UK. *Dementia*, 12, 682-696.
- INTERNATIONAL LONGEVITY CENTRE-UK 2013. The burden of constipation in our ageing population: working towards better solutions. International Longevity Centre-UK: International Longevity Centre-UK.
- IPHOFEN, R. 2009. *Ethical decision making in social research*, Basingstoke, Palgrave Macmillan.
- ISDEN, R., NORTON, M. & ABRAHAMS, C. 2013. The Dilnot social care cap: making sure it delivers for older people. London: Age UK.
- JABLONSKI, R., KOLANOWSKI, A., THERRIEN, B., MAHONEY, E., KASSAB, C. & LESLIE, D. 2011. Reducing care-resistant behaviors during oral hygiene in persons with dementia. *BMC Oral Health*, 11, 30.
- JANEVIC, M. R. & CONNELL, C. M. 2001. Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. *The Gerontologist*, 41, 334-347.
- JARROTT, S. E., ZARIT, S. H., STEPHENS, M. A. P., TOWNSEND, A. & GREENE, R. 2005. Instrumental help and caregivers' distress: effects of change in informal and formal help. *American Journal of Alzheimer's Disease and Other Dementias*, 20, 181-190.
- JENSEN, L., MÅNSSON, I., HOLTHE, T., HURNASTI, T. & GUÐNADÓTTIR, P. How assistive technology support cognitive disability, secure active living for persons with dementia and enhance new interfaces between formal and informal care in the area of dementia. Assistive Technology from adapted equipment to inclusive environments, 2009. AbleData, 222-227.
- JESSON, J. & LACEY, F. 2006. How to do (or not to do) a critical literature review. *Pharmacy Education*, 6, 139-148.
- JETTE, A. M. 2006. Toward a common language for function, disability, and health. *Physical Therapy*, 86, 726-734.

- JETTE, A. M. 2009. Toward a common language of disablement. *Journal of Gerontology*, 64A, 1165-1168.
- JOHANSSON, K., BORELL, L. & LILJA, M. 2009. Older persons' navigation through the service system towards home modification resources. *Scandinavian Journal of Occupational Therapy*, 16, 227-237.
- JOHNS, E., PHILLIPS, N., BELLEVILLE, S., GOUPIL, D., BABINS, L., KELNER, N., SKA, B., GILBERT, B., INGLIS, G., PANISSET, M., DE BOYSSON, C. & CHERTKOW, H. 2009. Executive functions in frontotemporal dementia and Lewy Body dementia. *Neuropsychology*, 23, 765-777.
- JOLING, K., VAN HOUT, H., SCHELTENS, P., VERNOOIJ-DASSEN, M., VAN DEN BERG, B., BOSMANS, J., GILLISSEN, F., MITTELMAN, M. & VAN MARWIJK, H. 2008. (Cost)-effectiveness of family meetings on indicated prevention of anxiety and depressive symptoms and disorders of primary family caregivers of patients with dementia: design of a randomized controlled trial. *BMC Geriatrics*, 8, 2.
- JONES, G. M. M. & VAN DER EERDEN, W. J. 2008. Designing care environments for persons with Alzheimer's disease: visuoperceptual considerations. *Reviews in Clinical Gerontology*, 18, 13-37.
- JUVA, K., MÄKELÄ, M., SULKAVA, R. & ERKINJUNTTI, T. 1997. One-year risk of institutionalization in demented outpatients with caretaking relatives. *International Psychogeriatrics*, 9, 175-182.
- KALES, H. C., BLOW, F. C., COPELAND, L. A., BINGHAM, R. C., KAMMERER, E. E. & MELLOW, A. M. 1999. Health care utilization by older patients with coexisting dementia and depression. *American Journal of Psychiatry*, 156, 550-556.
- KAPLAN, N. 2002. Hypertension and diabetes. *Journal of Human Hypertension*, 16, S56-S60.
- KARLSSON, E., AXELSSON, K., ZINGMARK, K. & SÄVENSTEDT, S. 2011. The challenge of coming to terms with the use of a new digital assistive device: a case study of two persons with mild dementia. *The Open Nursing Journal*, 5, 102-110.
- KATZ, S. 1983. Assessing self-maintenance: Activities of Daily Living, mobility and Instrumental Activities of Daily Living. *Journal of the American Geriatrics Society*, 31, 721-727.
- KAUP, B. A., LORECK, D., GRUBER-BALDINI, A. L., GERMAN, P., MENON, A. S., ZIMMERMAN, S., BURTON, L. & MAGAZINER, J. 2007. Depression and its relationship to function and medical status, by dementia status, in nursing home admissions. *The American Journal of Geriatric Psychiatry*, 15, 438-442.
- KELLEHEAR, A. 1993. *The unobtrusive researcher: A guide to methods*, Sydney, Allen & Unwin.
- KINGSTON, A., COLLERTON, J., DAVIES, K., BOND, J., ROBINSON, L. & JAGGER, C. 2012. Losing the ability in Activities of Daily Living in the oldest old: a hierarchical disability scale from the Newcastle 85+ study. *PLoS ONE*, 7, e31665.
- KITWOOD, T. 1995. Cultures of care: tradition and change. In: KITWOOD, T. & BENSON, S. (eds.) *The new culture of dementia care*. London: Hawker Publications.
- KITWOOD, T. 1997a. *Dementia reconsidered: the person comes first*, Buckingham, Open University Press.
- KITWOOD, T. 1997b. The experience of dementia. *Aging & Mental Health*, 1, 13-22.
- KITWOOD, T. 1997c. Personhood, dementia and dementia care. In: HUNTER, S. (ed.) *Dementia: challenges and new directions*. London: Jessica Kingsley.
- KNAPP, M. & PRINCE, M. 2007. *Dementia UK*. London: Alzheimer's Society.
- KOHLER-OCKMORE, J. & FENELEY, R. C. L. 1996. Long-term catheterization of the bladder. *British Journal of Urology*, 77, 347-351.
- KONTOS, P. C. 1998. Resisting institutionalization: constructing old age and negotiating home. *Journal of Aging Studies*, 12, 167-184.
- KROTHER, J. S. 1997. Giving voice to elderly people: community-based long term care. *Public Health Nursing*, 14, 217-226.

- KROUT, J. A. 1983. Knowledge and use of services by the elderly: a critical review of the literature. *The International Journal of Aging and Human Development*, 17, 153-167.
- KRULL, A. C. 2013. Health care professionals, friends, family and God: interactions contributing to caregivers' long-term care decisions. *Sociological Spectrum*, 33, 329-340.
- KUKULL, W. A., LARSON, E. B., TERI, L., BOWEN, J., MCCORMICK, W. & PFANSCHMIDT, M. L. 1994. The Mini-Mental State Examination score and the clinical diagnosis of dementia. *Journal of Clinical Epidemiology*, 47, 1061-1067.
- KVALE, S. & BRINKMANN, S. 2009. Interviews: learning the craft of qualitative research interview. Thousand Oaks, California: SAGE Publications, Ltd.
- KYLE, G. 2011. Managing dysphagia in older people with dementia. *British Journal of Community Nursing*, 16, 6-10.
- LANCIONI, G. E., LA MARTIRE, M. L., SINGH, N. N., O'REILLY, M. F., SIGAFOOS, J., PINTO, K. & MINERVINI, M. G. 2009a. Persons with mild or moderate Alzheimer's Disease managing daily activities via verbal instruction technology. *American Journal of Alzheimer's Disease and Other Dementias*, 23, 552-562.
- LANCIONI, G. E., PINTO, K., LA MARTIRE, M. L., TOTA, A., RIGANTE, V., TATULLI, E., PANSINI, E., MINERVINI, M. G., SINGH, N. N., O'REILLY, M. F., SIGAFOOS, J. & OLIVA, D. 2009b. Helping persons with mild or moderate Alzheimer's disease recapture basic daily activities through the use of an instruction strategy. *Disability and Rehabilitation*, 31, 211-219.
- LANCIONI, G. E., SINGH, N. N., O'REILLY, M. F., SIGAFOOS, J., BOSCO, A., ZONNO, N. & BADAGLIACCA, F. 2011. Persons with mild or moderate Alzheimer's disease learn to use urine alarms and prompts to avoid large urinary accidents. *Research in Developmental Disabilities*, 32, 1998-2004.
- LANDES, A. M., SPERRY, S. D. & STRAUSS, M. E. 2005. Prevalence of apathy, dysphoria and depression in relation to dementia severity in Alzheimer's disease. *Journal of Neuropsychiatry and Clinical Neuroscience*, 17, 342-349.
- LANGA, K., LLEWELLYN, D., LANG, I., WEIR, D., WALLACE, R., KABETO, M. & HUPPERT, F. 2009. Cognitive health among older adults in the United States and in England. *BMC Geriatrics*, 9, 23.
- LANGMORE, S. E., SKARUPSKI, K. A., PARK, P. S. & FRIES, B. E. 2002. Predictors of aspiration pneumonia in nursing home residents. *Dysphagia*, 17, 298-307.
- LAPLANTE, M. P., HARRINGTON, C. & KANG, T. 2002. Estimating paid and unpaid hours of personal assistance services in activities of daily living provided to adults living at home. *Health Services Research*, 37, 397-415.
- LAWRENCE, R. H. & JETTE, A. M. 1996. Disentangling the disablement process. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 51, S173-S182.
- LAWTON, J. 1998. Contemporary hospice care: The sequestration of the unbounded body and 'dirty dying'. *Sociology of Health and Illness*, 20, 121-143.
- LAWTON, M. 1982. Competence, environmental press, and the adaptation of older people. In: LAWTON, M., WINDLEY, P. & BYERTS, T. (eds.) *Aging and the environment: theoretical approaches*. New York: Garland STPM Press.
- LAWTON, M. & NAHEMOW, L. 1973. Ecology and the aging process. In: EISDORFER, C. & LAWTON, M. (eds.) *The psychology of adult development and aging*. Washington, DC: American Psychological Association.
- LAWTON, M. P. & BRODY, E. M. 1969. Assessment of older people: self-monitoring and instrumental activities of daily living. *Gerontologist*, 9, 179-186.
- LECHOWSKI, L., VAN PRADELLES, S., LE CRANE, M., D'ARAILH, L., TORTRAT, D., TEILLET, L. & VELLAS, B. 2010. Patterns of loss of basic activities of daily living in Alzheimer patients: a cross-sectional study of the French REAL cohort. *Dementia and Geriatric Cognitive Disorders*, 29, 46-54.

- LEE, M. & CHODOSH, J. 2009. Dementia and life expectancy: what do we know? *Journal of the American Medical Directors Association*, 10, 466-471.
- LEE, R. M. 1993. *Doing research on sensitive topics*, Thousand Oaks, California, SAGE Publications, Ltd.
- LEECE, J. & PEACE, S. 2010. Developing new understandings of independence and autonomy in the personalised relationship. *British Journal of Social Work*, 40, 1847-1865.
- LENKER, J. A. & PAQUET, V. L. 2003. A review of conceptual models for assistive technology outcomes research and practice. *Assistive Technology*, 15, 1-15.
- LEROI, I., WOOLHAM, J., GATHERCOLE, R., HOWARD, R., DUNK, B., FOX, C., O'BRIEN, J., BATEMAN, A., POLAND, F., BENTHAM, P., BURNS, A., DAVIES, A., FORSYTH, K., GRAY, R., KNAPP, M., NEWMAN, S., MCSHANE, R. & RITCHIE, C. 2013. Does telecare prolong community living in dementia? A study protocol for a pragmatic, randomised controlled trial. *Trials*, 14, 349.
- LESLIE, H. 2005. Urinary continence rehabilitation in the person with dementia. In: MARSHALL, M. (ed.) *Perspectives on rehabilitation and dementia*. London: Jessica Kingsley.
- LEVAC, D., COLQUHOUN, H. & O'BRIEN, K. K. 2010. Scoping studies: advancing the methodology. *Implementation Science*, 5, 69-77.
- LÉVESQUE, L., DUCHARME, F., LACHANCE, L., GERNER, L. A. & JIROVEC, M. M. 1999. Is there a difference between family caregiving of institutionalized elders with or without dementia? *Western Journal of Nursing Research*, 21, 472-497.
- LIBON, D. J., PRICE, C. C., DAVIS GARRETT, K. & GIOVANNETTI, T. 2004. From Binswanger's disease to leuokoaraiosis: what we have learned about subcortical vascular dementia. *The Clinical Neuropsychologist*, 18, 83-100.
- LIN, I.-F. & WU, H.-S. 2014. Activity limitations, use of assistive devices or personal help, and well-being: variation by education. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 69, S16-S25.
- LINCOLN, Y. S. & GUBA, E. G. 2000. The only generalization is: there is no generalization. In: GOMM, R., HAMMERSLEY, M. & FOSTER, P. (eds.) *Case study method*. London: SAGE Publications, Ltd.
- LISTON JR, E. H. 1978. Diagnostic delay in presenile dementia. *Journal of Clinical Psychiatry*, 39, 559-603.
- LITWAK, E., MESSERI, P. & SILVERSTEIN, M. 1990. The role of formal and informal groups in providing help to older people. In: UNGER, D. & SUSSMAN, M. (eds.) *Families in community settings: interdisciplinary perspectives*. New York: Hayworth.
- LLEWELLYN, D. J., LANG, I. A., LANGA, K. M. & HUPPERT, F. A. 2008. Cognitive function and psychological well-being: findings from a population-based cohort. *Age and Ageing*, 37, 685-689.
- LOBO, A., LAUNER, L. J., FRATIGLIONI, L., ANDERSEN, K., DI CARLO, A., BRETELER, M., COPELAND, J. R., DARTIGUES, J., JAGGER, C., MARTINEZ-LAGE, J., SOININEN, H. & HOFMAN, A. 1999. Prevalence of dementia and major subtypes in Europe: a collaborative study of population-based cohorts. Neurologic Diseases in the Elderly Research Group. *Neurology*, 54, 10-15.
- LÖFQVIST, C., NYGREN, C., BRANDT, Å. & IWARSSON, S. 2009. Very old Swedish women's experiences of mobility devices in everyday occupation: a longitudinal case study. *Scandinavian Journal of Occupational Therapy*, 16, 181-192.
- LÖFQVIST, C., NYGREN, C., SZÉMAN, Z. & IWARSSON, S. 2005. Assistive devices among very old people in five European countries. *Scandinavian Journal of Occupational Therapy*, 12, 181-192.
- LOH, P.-K. P. K., MAHER, S., GOLDSWAIN, P., FLICKER, L., RAMESH, P. & SALIGARI, J. 2005. Diagnostic accuracy of telehealth community dementia assessments. *Journal of the American Geriatrics Society*, 53, 2043-2044.

- LORD, K., LIVINGSTON, G. & COOPER, C. 2015. A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *International Psychogeriatrics*, 27, 1301-1312.
- LOVEJOY, W. S. 1991. A survey of algorithmic methods for partially observed Markov decision processes. *Annals of Operations Research*, 28, 47-65.
- LUBINSKI, R. & ORANGE, J. B. 1991. *Dementia and communication*, Toronto, BC Decker.
- LUPPA, M., LUCK, T., BRÄHLER, E., KÖNIG, H. H. & RIEDEL-HELLER, S. G. 2008. Prediction of institutionalisation in dementia. *Dementia & Geriatric Cognitive Disorders*, 26, 65-78.
- LUPPA, M., RIEDEL-HELLER, S. G., LUCK, T., WIESE, B., VAN DEN BUSSCHE, H., HALLER, F., SAUDER, M., MOSCH, E., PENTZEK, M., WOLLNY, A., EISELE, M., ZIMMERMANN, T., KONIG, H. H., MAIER, W., BICKEL, H., WERLE, J., WEYERER, S. & AGECODE STUDY, G. 2012a. Age-related predictors of institutionalization: results of the German study on Ageing, Cognition and Dementia in primary care patients (AgeCoDe). *Social Psychiatry and Psychiatric Epidemiology*, 47, 263-270.
- LUPPA, M., RIEDEL-HELLER, S. G., STEIN, J., LEICHT, H., KÖNIG, H. H., VAN DEN BUSSCHE, H., MAIER, W., SCHERER, M., BICKEL, H., MÖSCH, E., WERLE, J., PENTZEK, M., FUCHS, A., EISELE, M., JESSEN, F., TEBARTH, F., WIESE, B. & WEYERER, S. 2012b. Predictors of institutionalisation in incident dementia – results of the German study on Ageing, Cognition and Dementia in primary care patients (AgeCoDe study). *Dementia and Geriatric Cognitive Disorders*, 33, 282-288.
- LYKETSOS, C. G., STEELE, C., GALIK, E., ROSENBLATT, A., STEINBERG, M., WARREN, A. & SHEPPARD, J.-M. 1999. Physical aggression in dementia patients and its relationship to depression. *American Journal of Psychiatry*, 156, 66-71.
- LYMBERY, M. 2010. A new vision for adult social care? Continuities and change in the care of older people. *Critical Social Policy*, 30, 5-26.
- MAHMOOD, A., YAMAMOTO, T., LEE, M. & STEGGELL, C. 2008. Perceptions and use of gerotechnology: implications for aging in place. *Journal of Housing for the Elderly*, 22, 104-126.
- MAHONEY, D. F., PURTILO, R. B., WEBBE, F. M., ALWAN, M., BHARUCHA, A. J., ADLAM, T. D., JIMISON, H. B., TURNER, B. & BECKER, S. A. 2007. In-home monitoring of persons with dementia: ethical guidelines for technology research and development. *Alzheimer's & Dementia*, 3, 217-226.
- MAN-FUK LEUNG, E. 2000. Long-term care issues in the Asia-Pacific region. In: PHILLIPS, D. R. (ed.) *Ageing in the Asia-Pacific Region: issues and future trends*. New York, USA: Routledge.
- MANN, W. C., HURREN, D. & TOMITA, M. 1993. Comparison of assistive device use and needs of home-based older persons with different impairments. *The American Journal of Occupational Therapy*, 47, 980-987.
- MANN, W. C., HURREN, M. D., CHARVAT, B. A. & TOMITA, M. R. 1996. Changes over one year in assistive device use and home modifications by home-based older persons with Alzheimer's disease. *Topics in Geriatric Rehabilitation*, 12, 9-16.
- MANN, W. C., KARUZA, J., HURREN, D. & TOMITA, M. 1992. Assistive devices for home-based elderly persons with cognitive impairment. *Topics in Geriatric Rehabilitation*, 8, 35-52.
- MANN, W. C., KIMBLE, C., JUSTISS, M. D., CASSON, E., TOMITA, M. & WU, S. S. 2005. Problems with dressing in the frail elderly. *The American Journal of Occupational Therapy*, 59, 398-408.
- MANN, W. C., OTTENBACHER, K. J., FRAAS, L., TOMITA, M. & GRANGER, C. V. 1999. Effectiveness of assistive technology and environmental interventions in maintaining independence and reducing home care costs for the frail elderly. *Archives of Family Medicine*, 8, 210-217.
- MANTHORPE, J. & SAMSI, K. 2016. Person-centred dementia care: current perspectives. *Clinical Interventions in Aging*, 11, 1733-1740.

- MARMOT, M., BANKS, J., BLUNDELL, R., ERENS, B., LESSOF, C., NAZROO, J. & HUPPERT, F. 2014. English Longitudinal Study of Ageing: Waves 0-6, 1998-2013 21 ed. Colchester, Essex: UK Data Archive.
- MARMOT, M., OLDFIELD, Z., CLEMENS, S., BLAKE, M., PHELPS, A., NAZROO, J. & BANK, J. 2013. English Longitudinal Study of Ageing: Waves 0-5, 1998-2011. 20 ed. Colechester, Essex: UK Data Archive.
- MARSHALL, M., DUFF, P. & CULLEN, K. 2000. ASTRID: introducing assistive technology. *Journal of Dementia Care*, 8, 18-19.
- MARSHALL, M. & KATE, A. 2006. *Walking, not wandering. Fresh approaches to understanding and practice*, London, Hawker Publications.
- MARTIN, J. K., MARTIN, L. G., STUMBO, N. J. & MORRILL, J. H. 2011. The impact of consumer involvement on satisfaction with and use of assistive technology. *Disability and Rehabilitation: Assistive Technology*, 6, 225-242.
- MARTIN, S., CUNNINGHAM, C. & NUGENT, C. 2007. Ethical considerations for integrating technology into community-based service models for adults with dementia. *Alzheimer's Care Today*, 8, 251-258.
- MARTIN, W. & BARTLETT, H. 2003. Valuing people with dementia. In: ADAMS, T. & MANTHORPE, J. (eds.) *Dementia Care*. Great Britain: Arnold Publishers.
- MASE. 2010. *The MASE group: Monthly Alzheimer's Support Evening* [Online]. <http://themasegroup.org/>.
- MASLOW, A. H. 1943. A theory of human motivation. *Psychological Review*, 50, 370-396.
- MAYS, N., ROBERTS, E. & POPAY, J. 2001. Synthesising research evidence. In: FULOP, N., ALLEN, P., CLARKE, A. & BLACK, N. (eds.) *Studying the organisation and delivery of health services: research methods*. London: Routledge.
- MCCALLION, P., TOSELAND, R. W., GERBER, T. & BANKS, S. 2004. Increasing the use of formal services by caregivers of people with dementia. *Social Work*, 49, 441-450.
- MCCLENDON, M. J., SMYTH, K. A. & NEUNDORFER, M. M. 2006. Long-term-care placement and survival of persons with Alzheimer's Disease. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61, P220-P227.
- MCCREADIE, C. & TINKER, A. 2005. The acceptability of assistive technology to older people. *Ageing and Society*, 25, 91-110.
- MCCREADIE, C., WRIGHT, F. & TINKER, A. 2006. Improving the provision of information about assistive technology for older people. *Quality in Ageing and Older Adults*, 7, 13-22.
- MCDONNELL, A., JONES, M. L. & READ, S. 2000. Practical considerations in case study research: the relationship between methodology and process. *Journal of Advanced Nursing*, 32, 383-390.
- MELIN, L. & GÖTESTAM, K. G. 1981. The effects of rearranging ward routines on communication and eating behaviors of psychogeriatric patients. *Journal of Applied Behavior Analysis*, 14, 47-51.
- MENNE, H. L., TUCKE, S. S., WHITLATCH, C. J. & FEINBERG, L. F. 2008. Decision-making involvement scale for individuals with dementia and family caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 23, 23-29.
- MENTAL CAPACITY ACT 2005. Code of practice. *Department for Constitutional Affairs*. London: TSO.
- MENTAL HEALTH FOUNDATION. 2010. *Assessment of Mental Capacity Audit Tool* [Online]. <http://www.amcat.org.uk/>.
- MERTON, R. K., FISKE, M. & KENDALL, P. L. 1990. *The focused interview: a manual of problems and procedures*, New York, The Free Press.
- MIHAILIDIS, A., BARBENEL, J. C. & FERNIE, G. 2004a. The efficacy of an intelligent cognitive orthosis to facilitate handwashing by persons with moderate to severe dementia. *Neuropsychological Rehabilitation*, 14, 135-171.
- MIHAILIDIS, A., BOGER, J., CANIDO, M. & HOEY, J. 2007. The use of an intelligent prompting system for people with dementia. *Interactions*, 14, 34-37.

- MIHAILIDIS, A., BOGER, J., CRAIG, T. & HOEY, J. 2008. The COACH prompting system to assist older adults with dementia through handwashing: an efficacy study. *BMC Geriatrics*, 8, 28.
- MIHAILIDIS, A., CARMICHAEL, B. & BOGER, J. 2004b. The use of computer vision in an intelligent environment to support aging-in-place, safety, and independence in the home. *IEEE Transactions on Information Technology in Biomedicine*, 8, 238-247.
- MIHAILIDIS, A., FERNIE, G. & CLEGHORN, W. L. 2000. The development of a computerized cueing device to help people with dementia to be more independent. *Technology & Disability*, 13, 23-40.
- MIHAILIDIS, A. & FERNIE, G. R. 2002. Context-aware assistive devices for older adults with dementia. *Gerontechnology*, 2, 173-188.
- MILES, M. B. & HUBERMAN, A. M. 1994. *Qualitative data analysis: an expanded sourcebook*, Thousand Oaks, California, SAGE Publications, Ltd.
- MILES, T. P., FROELICH, T. E., BOGARDUS, S. T. & INOUE, S. K. 2001. Dementia and race: are there differences between African Americans and Caucasians? *Journal of the American Geriatrics Society*, 49, 477-484.
- MILLER, T., VELLEMAN, R., RIGBY, K., ORFORD, J., TOD, A., COPELLO, A. & BENNETT, G. 1997. The use of vignettes in the analysis of interview data. In: HAYES, N. (ed.) *Doing qualitative analysis in psychology*. East Sussex: Psychology Press Ltd.
- MILLS, M. A. & COLEMAN, P. G. 1994. Nostalgic memories in dementia - a case study. *The International Journal of Aging and Human Development*, 38, 203-219.
- MIRANDA-CASTILLO, C., WOODS, B., GALBODA, K., OOMMAN, S., OLOJUGBA, C. & ORRELL, M. 2010. Unmet needs, quality of life and support networks of people with dementia living at home. *Health and Quality of Life Outcomes*, 8, 132.
- MIYAMOTO, Y., TACHIMORI, H. & ITO, H. 2010. Formal caregiver burden in dementia: impact of behavioural and psychological symptoms of dementia and activities of daily living. *Geriatric Nursing*, 31, 246-253.
- MOLIN, G., PETTERSSON, C., JONSSON, O. & KEIJERA, U. 2007. Living at home with acquired cognitive impairment - can assistive technology help? *Technology & Disability*, 19, 91-101.
- MORGAN, D. G., SEMCHUK, K. M., STEWART, N. J. & D'ARCY, C. 2002. Rural families caring for a relative with dementia: barriers to use of formal services. *Social Science & Medicine*, 55, 1129-1142.
- MOUNTAIN, G. A. 2013. Using technology to support people with dementia. In: SIXSMITH, A. & GUTMAN, G. (eds.) *Technologies for active aging*. New York: Springer.
- MURAYAMA, S. & SAITO, Y. 2004. Neuropathological diagnostic criteria for Alzheimer's disease. *Neuropathology*, 24, 254-260.
- NAGI, S. 1965. Some conceptual issues in disability and rehabilitation. In: SUSSMAN, M. (ed.) *Sociology and rehabilitation*. Washington DC: American Sociological Association.
- NAGI, S. 1991. Disability concepts revised: implications for prevention. In: POPE, A. M. & TARLOV, A. R. (eds.) *Disability in America: toward a national agenda for prevention*. Washington DC: National Academy Press.
- NAIK, A. D. & GILL, T. M. 2005. Underutilization of environmental adaptations for bathing in community-living older persons. *Journal of the American Geriatrics Society*, 53, 1497-1503.
- NAMAZI, K. H. & JOHNSON, B. D. 1992. Dressing independently: a closet modification model for Alzheimer's disease patients. *American Journal of Alzheimer's Disease and Other Dementias*, 7, 22-28.
- NAMAZI, K. H. & JOHNSON, B. D. 1996. Issues related to behavior and the physical environment: bathing cognitively impaired patients. *Geriatric Nursing*, 17, 234-238.
- NATCEN SOCIAL RESEARCH 2014. English Longitudinal Study of Ageing (ELSA) Wave 1 to Wave 6 user guide to the core datasets. London, UK.
- NATIONAL AUDIT OFFICE 2017. Health and social care integration. England: National Audit Office.

- NATIONAL COLLABORATING CENTRE FOR MENTAL HEALTH 2006. Dementia: supporting people with dementia and their carers in health and social care. London: National Collaborating Centre for Mental Health.
- NEARY, D. & SNOWDEN, J. 1996. Fronto-temporal dementia: nosology, neuropsychology, and neuropathology. *Brain and Cognition*, 31, 176-187.
- NEGLEY, E. N. & MANLEY, J. T. 1990. Environmental interventions in assaultive behavior. *Journal of Gerontological Nursing*, 16, 29-33.
- NELSON, R. L. & FURNER, S. E. 2005. Risk factors for the development of fecal and urinary incontinence in Wisconsin nursing home residents. *Maturitas*, 52, 26-31.
- NETTLETON, S. 2013. *The sociology of health and illness*, Cambridge, Polity Press, Ltd.
- NEWMAN, A. B. & BRACH, J. S. 2001. Gender gap in longevity and disability in older persons. *Epidemiologic Reviews*, 23, 343-350.
- NHS COMMISSIONING ASSEMBLY 2015. Technology enabled care services: resource for commissioners. England: NHS England.
- NHS ENGLAND 2014. Five year forward view. England: NHS England.
- NOCHAJSKI, S., TOMITA, M. & MANN, W. 1996. An intervention study of the use and satisfaction with assistive devices by elderly persons with cognitive impairments. *Topics in Geriatric Rehabilitation*, 12, 40-53.
- NORBERG, A. & HIRSCHFELD, M. 1987. Feeding of severely demented patients in institutions: interviews with caregivers in Israel. *Journal of Advanced Nursing*, 12, 551-557.
- NORBURN, J. E. K., BERNARD, S. L., KONRAD, T. R., WOOMERT, A., DEFRIESE, G. H., KALSBECK, W. D., KOCH, G. G. & ORY, M. G. 1995. Self-care and assistance from others in coping with functional status limitations among a national sample of older adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 50, S101-S109.
- NOURHASHÉMI, F., AMOUYAL-BARKATE, K., GILLETTE-GUYONNET, S., CANTET, C. & VELLAS, B. 2005. Living alone with Alzheimer's disease: cross-sectional and longitudinal analysis in the REAL.FR study. *The Journal of Nutrition, Health and Aging*, 9, 117-120.
- NUGENT, C., MULVENNA, M., MOELAERT, F., BERGVALL-KÅREBORN, B., MEILAND, F., CRAIG, D., DAVIES, R., REINERSMANN, A., HETTINGA, M. & ANDERSSON, A.-L. 2007. Home based assistive technologies for people with mild dementia. In: OKADOME, T., YAMAZAKI, T. & MAKHTARI, M. (eds.) *Pervasive computing for quality of life enhancement*. Japan: Springer-Verlag Berlin Heidelberg.
- NYGÅRD, L. 2008. The meaning of everyday technology as experienced by people with dementia who live alone. *Dementia*, 7, 481-502.
- NYGÅRD, L. 2009. The stove timer as a device for older adults with cognitive impairment or dementia: different professionals' reasoning and actions. *Technology & Disability*, 21, 53-66.
- NYMAN, S. R. & VICTOR, C. R. 2014. Use of personal call alarms among community-dwelling older people. *Ageing & Society*, 34, 67-89.
- O'BRIEN, J. 2006. Vascular cognitive impairment. *The American Journal of Geriatric Psychiatry*, 14, 724-733.
- O'DONNELL, B. F., DRACHMAN, D. A., BARNES, H. J., PETERSON, K. E., SWEARER, J. M. & LEW, R. A. 1992. Incontinence and troublesome behaviors predict institutionalization in dementia. *Journal of Geriatric Psychiatry and Neurology*, 5, 45-52.
- OFFICE FOR NATIONAL STATISTICS 2014. Deaths registered in England and Wales (Series DR), 2013. <http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2013/stb-deaths-registered-in-england-and-wales-in-2013-by-cause.html>: Office for National Statistics.
- OFFICE FOR NATIONAL STATISTICS. 2015a. *Summary: UK population projected to reach 70 million by mid-2027* [Online]. <http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2010-based-projections/sum-2010-based-national-population-projections.html>.

- OFFICE FOR NATIONAL STATISTICS. 2015b. *What is life like for an older person today?* [Online]. <http://www.ons.gov.uk/ons/infographics/what-is-life-like-for-an-older-person-in-the-uk-today/index.html>.
- OLIVER, M. 1990. *The politics of disablement: critical texts in social work and the welfare state*, London, Macmillan Press.
- ORPWOOD, R., BJØRNEBY, S., HAGEN, I., MÄKI, O., FAULKNER, R. & TOPO, P. 2004. User involvement in dementia product development. *Dementia*, 3, 263-279.
- OUSLANDER, J. 2000. Intractable incontinence in the elderly. *BJU International*, 85, 72.
- PASSINI, R., PIGOT, H., RAINVILLE, C. & TÉTREAU, M.-H. 2000. Wayfinding in a nursing home for advanced dementia of the Alzheimer's type. *Environment and Behavior*, 32, 684-710.
- PEETERS, J., VAN BEEK, A., MEERVELD, J., SPREEUWENBERG, P. & FRANCKE, A. 2010. Informal caregivers of persons with dementia, their use of and needs for specific professional support: a survey of the National Dementia Programme. *BMC Nursing*, 9, 9.
- PERRY, R. H., IRVING, D., BLESSED, G., FAIRBAIRN, A. & PERRY, E. K. 1990. Senile dementia of Lewy body type: a clinically and neuropathologically distinct form of Lewy body dementia in the elderly. *Journal of the Neurological Sciences*, 95, 119-139.
- PETERS, C., WACHSMUTH, S. & HOEY, J. 2009. Learning to recognise behaviours of persons with dementia using multiple cues in an HMM-based approach. *Proceedings of the 2nd international conference on pervasive technologies related to assistive environments*. Corfu, Greece: ACM.
- PETERSEN, R. C., SMITH, G. E., WARING, S. C., IVNIK, R. J., TANGALOS, E. G. & KOKMEN, E. 1999. Mild cognitive impairment: clinical characterization and outcome. *Archives of Neurology*, 56, 303-308.
- PEW, R. W. & VAN HEMEL, S. B. 2004. *Technology for adaptive aging*, Washington, DC, National Academies Press.
- PHILLIPS, J., WALFORD, N. & HOCKEY, A. 2011. How do unfamiliar environments convey meaning to older people? Urban dimensions of placelessness and attachment. *International Journal of Ageing and Later Life*, 6, 73-102.
- PICKARD, L. 2003. Trends in and projections for informal care. In: COMAS-HERRERA, A. & WITTENBERG, R. (eds.) *European study of long-term care expenditure*. London: London School of Economics.
- PICKARD, L., WITTENBERG, R., COMAS-HERRERA, A., DAVIES, B. & DARTON, R. 2000. Relying on informal care in the new century? Informal care for elderly people in England to 2031. *Ageing and Society*, 20, 745-772.
- POLLACK, M. E. 2005. Intelligent technology for an aging population: the use of AI to assist elders with cognitive impairment. *The AI Magazine*, 26, 9-24.
- POPE, S. K., SHUE, V. M. & BECK, C. 2003. Will a healthy lifestyle help prevent Alzheimer's disease? *Annual Review of Public Health*, 24, 111-132.
- RABINS, P. V., MACE, N. L. & LUCAS, M. J. 1982. The impact of dementia on the family. *JAMA: Journal of the American Medical Association*, 248, 333-335.
- RAIVIO, M., ELONIEMI-SULKAVA, U., LAAKKONEN, M.-L., SAARENHEIMO, M., PIETILÄ, M., TILVIS, R. & PITKÄLÄ, K. 2007. How do officially organized services meet the needs of elderly caregivers and their spouses with Alzheimer's disease? *American Journal of Alzheimer's Disease and Other Dementias*, 22, 360-368.
- RAUHALA, M. & TOPO, P. 2003. Independent living, technology and ethics. *Technology & Disability*, 15, 205-214.
- REIFLER, B. V., LARSON, E. & HANLEY, R. 1982. Coexistence of cognitive impairment and depression in geriatric outpatients. *American Journal of Psychiatry*, 139, 623-626.
- REINDAL, S. M. 1999. Independence, dependence, interdependence: some reflections on the subject and personal autonomy. *Disability & Society*, 14, 353-367.

- REISBERG, B., FERRIS, S. H. & FRANSSEN, E. 1985. An ordinal functional assessment tool for Alzheimer's-type dementia. *Hospital & Community Psychiatry*, 36, 593-595.
- REMPADS. 2015. *RemPods* [Online]. <http://rempods.co.uk/>.
- RIALLE, V., OLLIVET, C., GUIGUI, C. & HERVE, C. 2008. What do family caregivers of Alzheimer's Disease patients desire in smart home technologies? *Methods of Information in Medicine*, 47, 63-69.
- RIIKONEN, M., MÄKELÄ, K. & PERÄLÄ, S. 2010. Safety and monitoring technologies for the homes of people with dementia. *Gerontechnology*, 9, 32-45.
- ROBERTS, L. W. 2003. Informed consent and the capacity for voluntarism. *FOCUS: The Journal of Lifelong Learning in Psychiatry*, 1, 407-414.
- ROBINSON, K. M., BUCKWALTER, K. C. & REED, D. 2005a. Predictors of use of services among dementia caregivers. *Western Journal of Nursing Research*, 27, 126-140.
- ROBINSON, L., HUGHES, J., DALEY, S., KEADY, J., BALLARD, C. & VOLICER, L. 2005b. End-of-life care and dementia. *Reviews in Clinical Gerontology*, 15, 135-148.
- ROBINSON, S. E. & FISHER, A. G. 1999. Functional and cognitive differences between cognitively-well people and people with dementia. *The British Journal of Occupational Therapy*, 62, 466-471.
- RODRIGUEZ, C. 2005. The role of medication in the rehabilitation of people with dementia. In: MARSHALL, M. (ed.) *Perspectives on rehabilitation and dementia*. London: Jessica Kingsley.
- ROSANO, C., SIMONSICK, E. M., HARRIS, T. B., KRITCHEVSKY, S. B., BRACH, J., VISSER, M., YAFFE, K. & NEWMAN, A. B. 2005. Association between physical and cognitive function in healthy elderly: the health, aging and body composition study. *Neuroepidemiology*, 24, 8-14.
- ROSE, N. 1989. *Governing the soul: technologies of human subjectivity*, London: Routledge.
- ROSENBERG, L., KOTTORP, A. & NYGÅRD, L. 2012. Readiness for technology use with people with dementia. *Journal of Applied Gerontology*, 31, 510-530.
- ROSENBERG, L. & NYGÅRD, L. 2012. Persons with dementia become users of assistive technology: a study of the process. *Dementia*, 11, 135-154.
- ROSSMAN, G. B. & WILSON, B. L. 1985. Numbers and words: combining quantitative and qualitative methods in a single large-scale evaluation study. *Evaluation Review*, 9, 627-643.
- ROY, P. C., BOUZOUANE, A., GIROUX, S. & BOUCHARD, B. 2011. Possibilistic activity recognition in smart homes for cognitively impaired people. *Applied Artificial Intelligence*, 25, 883-926.
- SABAT, S. R. & HARRÉ, R. 1992. The construction and deconstruction of self in Alzheimer's disease. *Ageing & Society*, 12, 443-443.
- SALMINEN, A.-L., BRANDT, Å., SAMUELSSON, K., TÖYTÄRI, O. & MALMIVAARA, A. 2009. Mobility devices to promote activity and participation: a systematic review. *Journal of Rehabilitation Medicine*, 41, 697-706.
- SANDERS, D. S., CARTER, M., D'SILVA, J., JAMES, G., BOLTON, R. & BARDHAN, K. 2000. Survival analysis in percutaneous endoscopic gastrostomy feeding: a worse outcome in patients with dementia. *The American Journal of Gastroenterology*, 95, 1472-1475.
- SARAFINO, E. 2006. *Health psychology: biopsychosocial interactions*, USA, John Wiley & Sons, Inc.
- SCHÄFER, I., HANSEN, H., SCHÖN, G., HÖFELS, S., ALTINER, A., DAHLHAUS, A., GENSICHEN, J., RIEDEL-HELLER, S., WEYERER, S., BLANK, W., KÖNIG, H.-H., VON DEM KNESEBECK, O., WEGSCHEIDER, K., SCHERER, M., VAN DEN BUSSCHE, H. & WIESE, B. 2012. The influence of age, gender and socio-economic status on multimorbidity patterns in primary care. first results from the multicare cohort study. *BMC Health Services Research*, 12, 89.
- SCHERER, M., JUTAI, J., FUHRER, M., DEMERS, L. & DERUYTER, F. 2007. A framework for modelling the selection of assistive technology devices (ATDs). *Disability & Rehabilitation: Assistive Technology*, 2, 1-8.
- SCHOFIELD, J. W. 2000. Increasing the generalizability of qualitative research. In: GOMM, R., HAMMERSLEY, M. & FOSTER, P. (eds.) *Case study method*. London: SAGE Publications, Ltd.

- SCHOLES, S., MEDINA, J., CHESHIRE, H., COX, K., HACKER, E. & LESSOF, C. 2009. Living in the 21st century: older people in England: the 2006 English Longitudinal Study of Ageing technical report. London: Institute of Fiscal Studies.
- SCHOLES, S., TAYLOR, R., CHESHIRE, H., COX, K. & LESSOF, C. 2008. Retirement, health and relationships of the older population in England: the 2004 English Longitudinal Study of Ageing Technical Report. London: Institute of Fiscal Studies.
- SCHULZ, R., BELLE, S. H., CZAJA, S. J., MCGINNIS, K. A., STEVENS, A. & ZHANG, S. 2004. Long-term care placement of dementia patients and caregiver health and well-being. *JAMA: The Journal of the American Medical Association*, 292, 961-967.
- SECKER, J., HILL, R., VILLENEAU, L. & PARKMAN, S. 2003. Promoting independence: but promoting what and how? *Ageing & Society*, 23, 375-391.
- SHARON, T. 2014. *Human nature in an age of biotechnology: the case for mediated posthumanism*, The Netherlands, Springer Netherlands.
- SHINOHARA, K. & WOBROCK, J. O. In the shadow of misperception: assistive technology use and social interactions. Proceedings of the SIGCHI conference on human factors in computing systems, 2011 New York. 705-714.
- SIEBENS, H., TRUPE, E., SIEBEN, A., COOK, F., ANSCEN, S., HANAUE, R. & OSTER, G. 1986. Correlates and consequences of eating dependency in institutionalized elderly. *Journal of the American Geriatrics Society*, 34, 192-198.
- SIMMONS, S. F. & SCHNELLE, J. F. 2006. Feeding assistance needs of long-stay nursing home residents and staff time to provide care. *Journal of the American Geriatrics Society*, 54, 919-924.
- SIMONS, H. 2009. *Case study research in practice*, London, SAGE Publications, Ltd.
- SIN, C. H. 2005. Seeking informed consent: reflections on research practice. *Sociology*, 39, 277-294.
- SINGH-MANOUX, A., AKBARALY, T. N., MARMOT, M., MELCHOIR, M., ANKRI, J., SABIA, S. & FERRIE, J. E. 2010. Persistent depressive symptoms and cognitive function in late midlife: the Whitehall II study. *Journal of Clinical Psychiatry*, 71, 1379-1385.
- SIXSMITH, A. 2000. An evaluation of an intelligent home monitoring system. *Journal of Telemedicine and Telecare*, 6, 63-72.
- SIXSMITH, A. 2006. New technologies to support independent living and quality of life for people with dementia. *Alzheimer's Care Today*, 7, 194-202.
- SIXSMITH, A., ORPWOOD, R. & TORRINGTON, J. 2007. Quality of life technologies for people with dementia. *Topics in Geriatric Rehabilitation*, 23, 85-93.
- SKOOG, I., NILSSON, L., PERSSON, G., LERNFELT, B., LANDAHL, S., PALMERTZ, B., ANDREASSON, L., ODEN, A. & SVANBORG, A. 1996. 15-year longitudinal study of blood pressure and dementia. *The Lancet*, 347, 1141-1145.
- SKYMNE, C., DAHLIN-IVANOFF, S., CLAEISSON, L. & EKLUND, K. 2012. Getting used to assistive devices: ambivalent experiences by frail elderly persons. *Scandinavian Journal of Occupational Therapy*, 19, 194-203.
- SLATER, R. 1995. *The psychology of growing old*, Buckingham, Open University Press.
- SLAUGHTER, S., ELIASZIW, M., MORGAN, D. & DRUMMOND, N. 2011. Incidence and predictors of eating disability among nursing home residents with middle-stage dementia. *Clinical Nutrition*, 30, 172-177.
- SLOANE, P. D., RADER, J., BARRICK, A.-L., HOEFFER, B., DWYER, S., MCKENZIE, D., LAVELLE, M., BUCKWALTER, K., ARRINGTON, L. & PRUITT, T. 1995. Bathing persons with dementia. *The Gerontologist*, 35, 672-678.
- SLOANE, P. D., ZIMMERMAN, S., SUCHINDRAN, C., REED, P., WANG, L., BOUSTANI, M. & SUDHA, S. 2002. The public health impact of Alzheimer's Disease, 2000-2050: potential implication of treatment advances. *Annual Review of Public Health*, 23, 213-231.
- SMYER, M. A. & QUALLS, S. H. 1999. *Aging and mental health*, Malden, Blackwell Publishing.

- SNYDER, A. R., PARSONS, J. T., MCLEOD, T. C. V., BAY, R. C., MICHENER, L. A. & SAUERS, E. L. 2008. Using disablement models and clinical outcomes assessment to enable evidence-based athletic training practice, part I: disablement models. *Journal of Athletic Training*, 43, 428-436.
- SOCIAL CARE INSTITUTE FOR EXCELLENCE 2013. Fair access to care services (FACS): prioritising eligibility for care and support.
<http://www.scie.org.uk/publications/guides/guide33/index.asp>.
- SOCIAL CARE INSTITUTE FOR EXCELLENCE 2014. Electronic surveillance in health and social care settings: a brief review.
http://www.cqc.org.uk/sites/default/files/CM111408_Item_8_Surveillance_literature_review_Appen_3.pdf.
- SOLDO, B. J. & MANTON, K. G. 1985. Changes in the health status and service needs of the oldest old: current patterns and future trends. *The Milbank Memorial Fund Quarterly. Health and Society*, 63, 286-319.
- SPAN, M., HETTINGA, M., VERNOOIJ-DASSEN, M., EEFTING, J. A. & SMITS, C. 2013. Involving people with dementia in the development of supportive IT applications: a systematic review. *Ageing Research Reviews*, 12, 535-551.
- SPIERS, N. A., MATTHEWS, R. J., JAGGER, C., MATTHEWS, F. E., BOULT, C., ROBINSON, T. G. & BRAYNE, C. 2005. Diseases and impairments as risk factors for onset of disability in the older population in England and Wales: from the Medical Research Council Cognitive Function and Ageing Study. *Journal of Gerontology*, 60A, 248-254.
- SPITZNAGEL, M. B., TREMONT, G., DAVIES, J. D. & FOSTER, S. M. 2006. Psychosocial predictors of dementia caregiver desire to institutionalize: caregiver, care recipient, and family relationship factors. *Journal of Geriatric Psychiatry and Neurology*, 19, 16-20.
- SPRUYTTE, N., VAN AUDENHOVE, C. & LAMMERTYN, F. 2001. Predictors of institutionalization of cognitively-impaired elderly cared for by their relatives. *International Journal of Geriatric Psychiatry*, 16, 1119-1128.
- ST-AMANT, O., WARD-GRIFFIN, C., DEFORGE, R. T., OUDSHOORN, A., MCWILLIAM, C., FORBES, D., KLOSECK, M. & HALL, J. 2012. Making care decisions in home-based dementia care: why context matters. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 31, 423-434.
- STAKE, R. E. 2000. Case studies. In: DENZIN, N. K. & LINCOLN, Y. S. (eds.) *Handbook of qualitative research*. Thousand Oaks, California: SAGE Publications, Ltd.
- STAKE, R. E. 2003. Case studies. In: DENZIN, N. K. & LINCOLN, Y. S. (eds.) *Strategies of qualitative inquiry*. Thousand Oaks, California: SAGE Publications, Ltd.
- STARKSTEIN, S. E., JORGE, R., MIZRAHI, R. & ROBINSON, R. G. 2005. The construct of minor and major depression in Alzheimer's disease. *American Journal of Psychiatry*, 162, 2086-2093.
- STAVROS, C. & WESTBERG, K. 2009. Using triangulation and multiple case studies to advance relationship marketing theory. *Qualitative Market Research: An International Journal*, 12, 307-320.
- STEPTOE, A., BREEZE, E., BANKS, J. & NAZROO, J. 2013. Cohort profile: the English Longitudinal Study of Ageing. *International Journal of Epidemiology*, 42, 1640-1648.
- STETLER, C. B., RITCHIE, J. A., RYCROFT-MALONE, J., SCHULTZ, A. A. & CHARNS, M. P. 2007. Improving quality of care through routine, successful implementation of evidence-based practice at the bedside: an organizational case study protocol using the Pettigrew and Whipp model of strategic change. *Implementation Science*, 2, 3.
- STETLER, C. B., RITCHIE, J. A., RYCROFT-MALONE, J., SCHULTZ, A. A. & CHARNS, M. P. 2009. Institutionalizing evidence-based practice: an organizational case study using a model of strategic change. *Implementation Science*, 4, 1-13.

- STEVENTON, A. & BARDSLEY, M. 2012. The impact of telehealth on use of hospital care and mortality. London: Nuffield Trust.
- STOCKWELL-SMITH, G., JONES, C. & MOYLE, W. 2011. 'You've got to keep account of heads all the time': staff perceptions of caring for people with dementia. *Journal of Research in Nursing*, 16, 400-412.
- STRAIN, L. A., BLANDFORD, A. A., MITCHELL, L. A. & HAWRANIK, P. G. 2003. Cognitively impaired older adults: risk profiles for institutionalization. *International Psychogeriatrics*, 15, 351-366.
- STRANDGAARD, S. 1996. Hypertension and stroke. *Journal of Hypertension*, 14, S23-S27.
- STUART-HAMILTON, I. 2006. *The psychology of ageing: an introduction*, London, Jessica Kingsley.
- SUSSMAN, T. & REGEHR, C. 2009. The influence of community-based services on the burden of spouses caring for their partners with dementia. *Health & Social Work*, 34, 29-39.
- SWANSON, K. A. & CARNAHAN, R. M. 2007. Dementia and comorbidities: an overview of diagnosis and management. *Journal of Pharmacy Practice*, 20, 296-317.
- TAATI, B., SNOEK, J. & MIHAILIDIS, A. Towards aging-in-place: automatic assessment of product usability for older adults with dementia. First IEEE international conference on healthcare informatics, imaging and systems biology (HISB), 2011 San Jose, California. 205-212.
- TAGHIZADEH LARSSON, A. & ÖSTERHOLM, J. H. 2014. How are decisions on care services for people with dementia made and experienced? A systematic review and qualitative synthesis of recent empirical findings. *International Psychogeriatrics*, 26, 1849-1862.
- TALLEY, N. J., JONES, M., NUYTS, G. & DUBOIS, D. 2003. Risk factors for chronic constipation based on a general practice sample. *The American Journal of Gastroenterology*, 98, 1107-1111.
- TAYLOR, R., CONWAY, L., CALDERWOOD, L., LESSOF, C., CHESHIRE, H., COX, K. & SCHOLLES, S. 2007. Health, wealth and lifestyles of the older population in England: the 2002 English Longitudinal Study of Ageing technical report. London: Institute of Fiscal Studies.
- TECHNOLOGY TO CARE. 2014. *Embedding electronic Assistive Technologies (eATs) in social care* [Online]. Available: <http://www.technologytocare.org.uk/>.
- TELLIS, W. 1997. *Application of a case study methodology* [Online]. <http://www.nova.edu/ssss/QR/QR3-3/tellis2.html>.
- THE BRITISH PSYCHOLOGICAL SOCIETY. 2010. *Audit Tool for Mental Capacity Assessments* [Online]. <http://www.scie.org.uk/publications/mca/audits/files/britishpsychologicalsociety.pdf>: Professional Practice Board and Social Care Institute for Excellence.
- THE INSTITUTE FOR FISCAL STUDIES. 2011a. *ELSA Timetable* [Online]. <http://www.elsa-project.ac.uk/timetable>.
- THE INSTITUTE FOR FISCAL STUDIES. 2011b. *Insight into a maturing population* [Online]. <http://www.elsa-project.ac.uk/>.
- THE NATIONAL ARCHIVES. 2009. *The preventative technology grant* [Online]. Available: http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_5464107.
- THOMAS, C. 2007. *Sociologies of disability and illness: contested ideas in disability studies and medical sociology*, Hampshire, Palgrave Macmillan.
- TINKER, A. 2007. Ethics and older people. In: LEATHARD, A. & MCLAREN, S. (eds.) *Ethics: contemporary challenges in health and social care*. Bristol, UK: The Policy Press.
- TINKER, A., KELLAHER, L., GINN, J. & RIBE, E. 2013. Assisted living platform: the long term care revolution. London: King's College London.
- TWIGG, J. 2000. Carework as a form of bodywork. *Ageing and Society*, 20, 389-412.
- TWIGG, J. 2010. Clothing and dementia: a neglected dimension? *Journal of Aging Studies*, 24, 223-230.
- UK PARLIAMENT 1970. Chronically Sick and Disabled Persons Act 1970. <http://www.legislation.gov.uk/ukpga/1970/44/contents>.

- UK PARLIAMENT 1996. Housing Grants, Construction and Regeneration Act 1996.
<http://www.legislation.gov.uk/ukpga/1996/53/contents>.
- UK PARLIAMENT 1998. Data Protection Act 1998.
<http://www.legislation.gov.uk/ukpga/1998/29/contents>.
- UK PARLIAMENT 2000. Freedom of Information Act 2000.
<http://www.legislation.gov.uk/ukpga/2000/36/contents>.
- UK PARLIAMENT 2003. Community Care (Delayed Discharges etc.) Act 2003.
<http://www.legislation.gov.uk/ukpga/2003/5>.
- UK PARLIAMENT 2005. Mental Capacity Act 2005.
<http://www.legislation.gov.uk/ukpga/2005/9/contents>.
- UK PARLIAMENT 2014. Care Act 2014.
<http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm>.
- VACHER, M., PORTET, F., FLEURY, A. & NOURY, N. 2013. Development of audio sensing technology for ambient assisted living: applications and challenges. In: RODRIGUES, J. (ed.) *Digital Advances in Medicine, E-Health, and Communication Technologies*. United States of America: IGI Global.
- VAISMORADI, M., TURUNEN, H. & BONDAS, T. 2013. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*, 15, 398-405.
- VAN DER STEEN, J. T., RIBBE, M. W., DELIENS, L., GUTSCHOW, G. & ONWUTEAKA-PHILIPSEN, B. D. 2014. Retrospective and prospective data collection compared in the Dutch End of Life in Dementia (DEOLD) study. *Alzheimer Disease & Associated Disorders*, 28, 88-94.
- VAN HOOFF, J. & KORT, H. S. M. 2009. Supportive living environments: a first concept of a dwelling designed for older adults with dementia. *Dementia*, 8, 293-316.
- VAN HOOFF, J., KORT, H. S. M., VAN WAARDE, H. & BLOM, M. M. 2010. Environmental interventions and the design of homes for older adults with dementia: an overview. *American Journal of Alzheimer's Disease and Other Dementias*, 25, 202-232.
- VELLAS, B., GAUTHIER, S., ALLAIN, H., ANDRIEU, S., AQUINO, J. P., BERRUT, G., BERTHEL, M., BLANCHARD, F., CAMUS, V., DARTIGUES, J.-F., DUBOIS, B., FORETTE, F., FRANCO, A., GONTHEIR, R., GRAND, A., HERVY, M.-P., JEANDEL, C., JOEL, M. E., JOUANNY, P., LEBERT, F., MICHOT, P., MONTASTRUC, J. L., NOURHASHEMI, F., OUSSET, P. J., PARIENTE, J., RIGAUD, A. S., ROBERT, P., RUALT, G., STRUBEL, D., TOUCHON, J., VERNY, M. & VETEL, J. M. 2005. Consensus statement on dementia of Alzheimer type in the severe stage. *Journal of Nutrition, Health and Aging*, 9, 330-338.
- VERBRUGGE, L. M. & JETTE, A. M. 1994. The disablement process. *Social Science & Medicine*, 38, 1-14.
- VERBRUGGE, L. M., RENNERT, C. & MADANS, J. H. 1997. The great efficacy of personal and equipment assistance in reducing disability. *American Journal of Public Health*, 87, 384-392.
- VERBRUGGE, L. M. & SEVAK, P. 2002. Use, type, and efficacy of assistance for disability. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 57, S366-S379.
- VERNON, A. & QURESHI, H. 2000. Community care and independence: self-sufficiency or empowerment? *Critical Social Policy*, 20, 255-276.
- VISSE, M. 2015. *The rituals of dinner: the origins, evolution, eccentricities, and meaning of table manners*, New York, Open Road Media.
- VITALIANO, P. P., RUSSO, J., BREEN, A. R., VITIELLO, M. V. & PRINZ, P. N. 1986. Functional decline in the early stages of Alzheimer's disease. *Psychology & Aging*, 1, 41-46.
- VITTORIA, A. K. 1998. Preserving selves: Identity, work and dementia. *Research on Aging*, 20, 91-136.
- VLACHANTONI, A., SHAW, R., EVANDROU, M. & FLALKINGHAM, J. 2013. The determinants of receiving social care in later life in England. *Ageing & Society*, 1-25.

- WACKERBARTH, S. 1999. What decisions are made by family caregivers? *American Journal of Alzheimer's Disease*, 14, 111-119.
- WACKERBARTH, S. & JOHNSON, M. M. S. 1999. Predictors of driving cessation, independent living, and power of attorney decisions by dementia patients and caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 14, 283-288.
- WAHL, H.-W., FÄNGE, A., OSWALD, F., GITLIN, L. N. & IWARSSON, S. 2009. The home environment and disability-related outcomes in aging individuals: what is the empirical evidence? *The Gerontologist*, 49, 353-367.
- WAI, A. A. P., FOOK, V. F. S., JAYACHANDRAN, M., BISWAS, J., NUGENT, C., MULVENNA, M., LEE, J.-E. & KIAT, P. Y. L. 2008. Smart wireless continence management system for persons with dementia. *Telemedicine and e-health*, 14, 825-832.
- WALKER, A. 2005. In the absence of food: a case of rhythmic loss and spoiled identity for patients with percutaneous endoscopic gastrostomy feeding tubes. *Food, Culture and Society: An International Journal of Multidisciplinary Research*, 8, 161-180.
- WARNER, J., MCCARNEY, R., GRIFFIN, M., HILL, K. & FISHER, P. 2008. Participation in dementia research: Rates and correlates of capacity to give informed consent. *Journal of Medical Ethics*, 34, 167-170.
- WATSON, R. 2003. Addressing the physical care needs of people with dementia. In: ADAMS, T. & MANTHORPE, J. (eds.) *Dementia Care*. Great Britain: Arnold Publishers.
- WATSON, R. & GREEN, S. 2006. Feeding and dementia: a systematic literature review. *Journal of Advanced Nursing*, 54, 86-93.
- WATTMO, C., WALLIN, Å. K., LONDOS, E. & MINTHON, L. 2011. Risk factors for nursing home placement in Alzheimer's disease: a longitudinal study of cognition, ADL, service utilization, and cholinesterase inhibitor treatment. *The Gerontologist*, 51, 17-27.
- WEBB, T. & SHEERAN, P. 2006. Does changing behavioral intentions engender behavior change? A meta-analysis of the experimental evidence. *Psychological Bulletin*, 132, 249-268.
- WEINTRAUB, D., RASKIN, A., RUSKIN, P. E., GRUBER-BALDINI, A. L., ZIMMERMAN, S. I., HEBEL, J. R., GERMAN, P. & MAGAZINER, J. 2000. Racial differences in the prevalence of dementia among patients admitted to nursing homes. *Psychiatric Services*, 51, 1259-1264.
- WENGRAF, T. 2001. *Qualitative research interviewing: biographic narrative and semi-structured methods*, London, SAGE Publications, Ltd.
- WESSELS, R., DIJCKS, B., SOEDE, M., GELDERBLUM, G. & DE WITTE, L. 2003. Non-use of provided assistive technology devices, a literature overview. *Technology and Disability*, 15, 231-238.
- WEY, S. 2005. One size does not fit all: person-centred approaches to the use of Assistive Technology. In: MARSHALL, M. (ed.) *Perspectives on rehabilitation and dementia*. London: Jessica Kingsley Publishers.
- WHERTON, J. P. & MONK, A. F. 2008. Technological opportunities for supporting people with dementia who are living at home. *International Journal of Human-Computer Studies*, 66, 571-586.
- WHITMER, R., GUSTAFSON, D., BARRETT-CONNOR, E., HAAN, M., GUNDERSON, E. & YAFFE, K. 2008. Central obesity and increased risk of dementia more than three decades later. *Neurology*, 71, 1057-1064.
- WIELANDT, T., MCKENNA, K., TOOTH, L. & STRONG, J. 2006. Factors that predict the post-discharge use of recommended assistive technology (AT). *Disability and Rehabilitation: Assistive Technology*, 1, 29-40.
- WILBERFORCE, M., CHALLIS, D., DAVIES, L., KELLY, M. P., ROBERTS, C. & CLARKSON, P. 2016a. Person-centredness in the community care of older people: a literature-based concept synthesis. *International Journal of Social Welfare*, 26, 86-98.

- WILBERFORCE, M., CHALLIS, D., DAVIES, L., KELLY, M. P., ROBERTS, C. & LOYNES, N. 2016b. Person-centredness in the care of older adults: a systematic review of questionnaire-based scales and their measurement properties. *BMC Geriatrics*, 16, 63-74.
- WILES, R., CROW, G., CHARLES, V. & HEATH, S. 2007. *Informed consent and the research process: following rules or striking balances?* [Online].
<http://www.socresonline.org.uk/12/2/wiles.html>.
- WILKIN, D. 1987. Conceptual problems in dependency research. *Social Science & Medicine*, 24, 867-873.
- WILLIAMS, G. H. & WOOD, P. H. N. 1988. Coming to terms with chronic illness: the negotiation of autonomy in rheumatoid arthritis. *International Disability Studies*, 10, 128-133.
- WIMO, A., VON STRAUSS, E., NORDBERG, G., SASSI, F. & JOHANSSON, L. 2002. Time spent on informal and formal care giving for persons with dementia in Sweden. *Health Policy*, 61, 255-268.
- WINSTEIN, C. J., REQUEJO, P. S., ZELINSKI, E. M., MULROY, S. J. & CRIMMINS, E. M. 2012. A transformative subfield in rehabilitation science at the nexus of new technology, aging, and disability. *Frontiers in Psychology*, 3, 1-8.
- WINTER, L., GITLIN, L. N. & DENNIS, M. 2011. Desire to institutionalize a relative with dementia: quality of premorbid relationship and caregiver gender. *Family Relations*, 60, 221-230.
- WOLFS, C. A. G., DE VUGT, M. E., VERKAAIK, M., HAUFE, M., VERKADE, P. J., VERHEY, F. R. J. & STEVENS, F. 2012. Rational decision-making about treatment and care in dementia: a contradiction in terms? *Patient Education and Counseling*, 87, 43-48.
- WOODS, B. 1999. Promoting well-being and independence for people with dementia. *International Journal of Geriatric Psychiatry*, 14, 97-105.
- WOODS, B. & PRATT, R. 2005. Awareness in dementia: ethical and legal issues in relation to people with dementia. *Aging & Mental Health*, 9, 423-429.
- WOOLHAM, J. 2006. Assistive Technology, telecare, and dementia: some implications of current policies and guidance. *Research Policy and Planning*, 24, 149-164.
- WOOLHAM, J. & FRISBY, B. 2002. Building a local infrastructure that supports the use of Assistive Technology in the care of people with dementia. *Research Policy and Planning*, 20, 11-24.
- WORLD HEALTH ORGANIZATION 2004. A glossary of terms for community health care and services for older persons. WHO Centre for Health Development.
- WRIGHT, F. 2000. The role of family care-givers for an older person resident in a care home. *British Journal of Social Work*, 30, 649-661.
- WRIGHT, F., MCCREADIE, C. & TINKER, A. 2005. Improving the provision of information about assistive technology for older people. Report to Helen Hamlyn Foundation. London: Age Concern Institute of Gerontology.
- WRIGHT, F., MCCREADIE, C. & TINKER, A. 2006. Improving the provisions of information about assistive technology for older people. *Quality in Ageing and Older Adults*, 7, 13-22.
- YIN, R. K. 2003a. *Applications of case study research*, Thousand Oaks, California, SAGE Publications, Ltd.
- YIN, R. K. 2003b. *Case study research: design and methods*, Thousand Oaks, California, SAGE Publications, Ltd.
- YIN, R. K. 2014. *Case study research: design and methods*, Los Angeles, SAGE Publications, Ltd.
- YOUNG, Y. 2009. Factors associated with permanent transition from independent living to nursing home in a continuing care retirement community. *Journal of the American Medical Directors Association*, 10, 491-497.
- ZARIT, S. H., GAUGLER, J. E. & JARROTT, S. E. 1999. Useful services for families: research findings and directions. *International Journal of Geriatric Psychiatry*, 14, 165-178.

- ZEKRY, D., HERRMANN, F. R., GRANDJEAN, R., VITALE, A., DE PINHO, M., MICHEL, J., GOLD, G. & KRAUSE, K. 2009. Does dementia predict adverse hospitalization outcomes? A prospective study in aged inpatients. *International Journal of Geriatric Psychiatry*, 24, 283-291.
- ZIADY, L. E. & SMALL, N. 2005. *Prevent and Control Infection: Application Made Easy*, Juta and Company Ltd.
- ZIMMERMAN, S. J. & SLOANE, P. D. 1999. Optimum residential care for people with dementia. *Generations*, 23, 62-68.
- ZINGMARK, M. & BERNSPÅNG, B. 2011. Meeting the needs of elderly with bathing disability. *Australian Occupational Therapy Journal*, 58, 164-171.

Appendices

Appendix number and title	Contents	Page number
Appendix 1: Mini-Mental State Examination	Mini-Mental State Examination	307
	Administration notes	308
Appendix 2: Literature search strategy for the scoping review	Flowchart of three phases of literature search strategy for scoping review	309
	Keywords and phrases used when identifying relevant literature	310
	Example of review table for extracting key information from literature	311
	Frequency and percentages of literature in summary tables for numerical analysis	312
Appendix 3: ELSA analysis	Waves of ELSA	317
	Creation of new dataset variables	318
Appendix 4: Study design - materials and instruments	SCREC ethical approval confirmation	319
	Scan of CRB check	323
	Research protocol summary and data collection flowcharts	324
	Procedure for Breaking Confidentiality	328
	AMCAT Audit Report Outcome	329
	Procedure for Those who Become Distressed	333
	Flowcharts of Stage One participant numbers	334
	Care mapping framework	339
	Pre Data Collection Family Letter and Pre Data Collection Form	340
	Resident Information Sheet	345
	Assessment of Capacity Form and Supported Decision-Making Form	347
	Resident Consent Form	350
	Courtesy letter for families whose relative gave their own consent	352
	Personal Consultee Letter and Personal Consultee Form	353
	Flowcharts of Stage Two participant numbers	357
	Family and friends' interview topics	361
	Keyworkers' interview topics	364
	Interview Invitation Pack for family and friends: Invitation Letter, Study Form, and Information Sheet	366
	Interview Invitation Pack for keyworkers: Invitation Letter, Study Form, and Information Sheet	372
	Interviewee Consent Form	378
Appendix 5: Stage One vignettes	Case A Stage One vignette	380
	Case B Stage One vignette	383
	Case C Stage One vignette	385
	Case D Stage One vignette	388
	Case E Stage One vignette	390
	Case F Stage One vignette	392
	Case G Stage One vignette	394
	Case H Stage One vignette	396
	Case I Stage One vignette	399
	Case J Stage One vignette	401
	Case K Stage One vignette	403
	Case L Stage One vignette	406
	Case M Stage One vignette	408

	Case N Stage One vignette	410
	Case O Stage One vignette	412
	Case P Stage One vignette	414
6: Stage Two case studies	Case A case study	416
	Case B case study	430
	Case C case study	438
	Case D case study	446
	Case E case study	454
	Case F case study	461
	Case G case study	468
	Case H case study	475
	Case I case study	481
	Case J case study	488
7: Thematic analysis	Initial themes resulting from first level of analysis	495
	Potential themes resulting from second level of analysis	498

Appendix 1: Mini-Mental State Examination

Source: Folstein et al. (1975)

Patient: _____ Examiner: _____ Date: _____

Maximum Score: _____ Score: _____

ORIENTATION

5 () What is the: (year) (season) (date) (day) (month)?

5 () Where are we: (state) (county) (town) (hospital) (floor)?

REGISTRATION

3 () Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he learns all 3. Count trials and record.

Trials: _____

ATTENTION AND CALCULATION

5 () Serial 7's. 1 point for each correct. Stop after 5 answers. Alternatively, spell "world" backwards.

RECALL

3 () Ask for the 3 objects repeated above. Give 1 point for each correct.

LANGUAGE

9 () Name a pencil, and watch (2 points)
Repeat the following "No ifs, ands or buts." (1 point)
Follow a 3-stage command: "Take a paper in your right hand, fold it in half, and put it on the floor" (3 points)
Read and obey the following: CLOSE YOUR EYES (1 point)
Write a sentence (1 point)
Copy design (1 point)

Total score: _____

ASSESS level of consciousness along a continuum: Alert--Drowsy--Stupor--Coma

Administration notes

ORIENTATION

Ask for the date. Then ask specifically for parts omitted, e.g., “Can you also tell me what season it is?” One point for each correct.

Ask in turn “Can you tell me the name of this hospital?” (town, county, etc.). One point for each correct.

REGISTRATION

Ask the patient if you may test his memory. Then say the names of 3 unrelated objects, clearly and slowly, about one second for each. After you have said all 3, ask him to repeat them. This first repetition determines his score (0-3) but keep saying them until he can repeat all 3, up to 6 trials. If he does not eventually learn all 3, recall cannot be meaningfully tested.

ATTENTION AND CALCULATION

Ask the patient to begin with 100 and count backwards by 7. Stop after 5 subtractions (93, 86, 79, 72, 65). Score the total number of correct answers.

If the patient cannot or will not perform this task, ask him to spell the word “world” backwards. The score is the number of letters in correct order. E.g. dlrow = 5, dlrow = 3.

RECALL

Ask the patient if he can recall the 3 words you previously asked him to remember. Score 0-3.

LANGUAGE

Naming: Show the patient a wrist watch and ask him what it is. Repeat for pencil. Score 0-2.

Repetition: Ask the patient to repeat the sentence after you. Allow only one trial. Score 0 or 1.

3-Stage command: Give the patient a piece of plain blank paper and repeat the command. Score 1 point for each part correctly executed.

Reading: On a blank piece of paper print the sentence “Close your eyes”, in letters large enough for the patient to see clearly. Ask him to read it and do what it says. Score 1 point only if he actually closes his eyes.

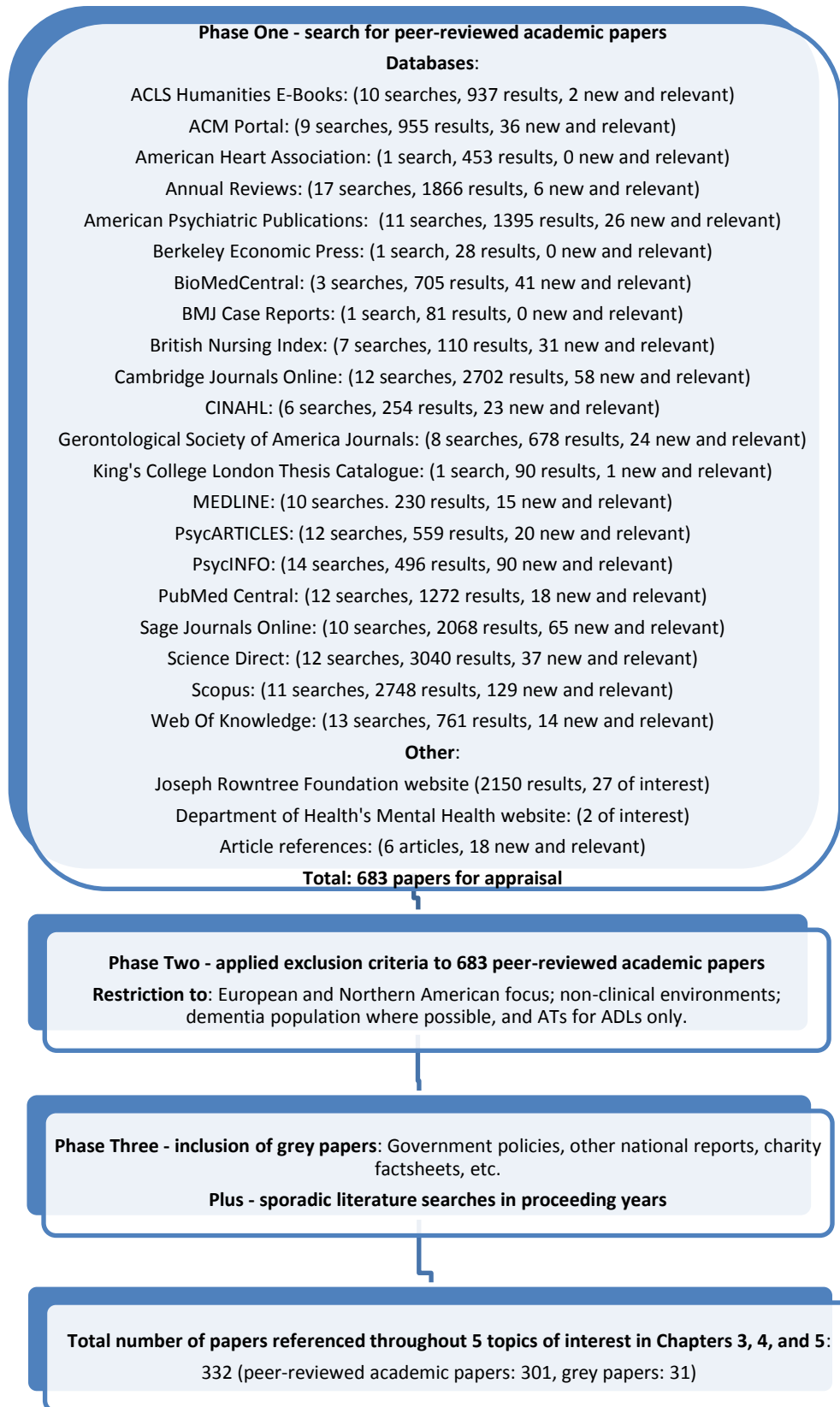
Writing: Give the patient a blank piece of paper and ask him to write a sentence for you. Do not dictate a sentence, it is to be written spontaneously. It must contain a subject and verb and be sensible. Correct grammar and punctuation are not necessary.

Copying: On a clean piece of paper, draw intersecting pentagons, each side about 1 in., and ask him to copy it exactly as it is. All 10 angles must be present and 2 must intersect to score 1 point. Tremor and rotation are ignored.

Estimate the patient’s level of sensorium along a continuum, from alert on the left to coma on the right.

Appendix 2: Literature search strategy for the scoping review

Flowchart of three phases of literature search strategy for scoping review



Keywords and phrases used when identifying relevant literature

Topic	Key words and phrases
ADLs	ADLs: “Activities of Daily Living”, “Instrumental Activities of Daily Living”, activity, hygiene, groom* (-s, -ed, -ing), brushing hair, brushing teeth, oral hygiene, dress* (-ed, -ing), hand washing, toilet* (-s, -ing), continence, incontinence, bath* (-es, -ed, -ing, -room), transferring, walk* (-s, -ed, -ing), mov* (-e, -ing), mobil* (-e, -ity), eat* (-ing, -s), feed* (-ing, -s), knife, fork, plate, handrail
ATs	“Assistive Technology”, AT, technolog* (-y-, -ical), assist* (-ive, -ed, -ing), “Assisted Living”
Dementia and cognition	Dementia, Alzheimer’s, “Alzheimer’s disease”, “mild cognitive impairment”, MCI, memory, depression, anxiety, cognitive
Older people	“Older adults”, elderly, old* (-er)
Physical or disability	Functionality, disability, difficulty, impairment, gait
Carers, formal and informal	Family, relationship, “family carer”, “informal carer”, familial, carer, nurse, professional, medical staff
Formal services	Services, “care at home”, “formal care”
Care homes, institutionalisation and relocation decisions	“Care home”, “residential home”, residential, “nursing home”, institution* (-alisation, -ed), “leaving home”, “care home entry”, decision
Policies	“Dementia policy”, “dementia policies”, “dementia report”, “older people’s policies”
Methods and methodology	“Case stud* (-y, -ies)”, “mixed-methods”, qualitative, map* (-s, -ped, -ping), “care records”, interviews, “interviews with carers”, quantitative, prediction, “English Longitudinal Study of Ageing”, ELSA, ethic* (-s, -al)

Example of review table for extracting key information from literature

Reference and type of publication	Location and data used	Target population and/or sample size	Aim	AT	Study design and strength of evidence	Findings	How referenced in Chapter 3 for topic of cognitive and physical difficulties on ADL disability, and/or thoughts and implications for thesis
Agree and Freedman (2003). Research article. Quantitative data.	USA. Secondary data using samples from the 1994–1995 National Health Interview Survey Phase 2 Disability Supplements in USA.	Adults with disability in bathing and mobility: transferring, walking, and getting outside.	Compare type of long term care (human assistance or use of ATs) on unmet need and residual difficulty (pain, fatigue, and time intensity).	Bathing: hand rails, bath stools, or chairs. Transferring: canes, walkers, special cushions, lift chairs, hospital bed, and a trapeze or sling. Walking and going outside: canes, walkers, crutches, and wheelchairs.	Theoretical framework closely aligned to disablement process model and concept of underlying and residual disability. Multivariate analysis to compare samples. Non-experimental, cross-sectional design.	ATs do not help three dimensions of residual difficulty, yet reports less unmet need than those who have human assistance. AT users do not want human assistance even if they have more pain, etc. Generally though AT-only users have less underlying disability.	Model of underlying and residual disability to explore institutionalisation in Chapter 5. ATs can expand bodily capabilities and reduce environmental demand. However, continued focus on mobility rather than ADLs; sample sizes for dressing, eating, and toileting too small. Study not dementia-specific.
Allen et al. (2001). Research article. Quantitative data.	Canada and USA. Secondary data using the Adult Followback Survey of the Disability Supplement to the 1994 and 1995 National Health Interview Survey (NHIS-D).	9,230 adults who reported both mobility and difficulty with ADLs.	To investigate use of mobility equipment as a substitute for human assistance, and whether this saves money for formal care services.	Canes, crutches, walkers and wheelchairs.	Regression analyses. Non-experimental, cross-sectional design.	Use of canes and crutches (but not walkers and wheelchairs) reduced weekly formal and informal hours of care, and lowered costs.	Socio-medical model of disability may be best used for theory concerning contribution of ATs to ADL disability. Mobility-related ATs not for ADLs. Substitution and supplementation debate: canes and crutches can substitute but not more complex devices (frames and wheelchairs). Study not dementia-specific.

Frequency and percentages of literature in summary tables for numerical analysis

Country of origin:

N=332. Percentages are rounded to the nearest full percentage point.

Country of origin	Frequency	Percentage of 332
USA	129	39
UK	89	27
Canada	27	8
Sweden	12	4
Netherlands	9	3
France	6	2
Finland	4	1
Ireland	3	1
Mix EU (incl. UK)	11	3
USA and EU	1	0
USA and Canada	3	1
Canada and UK	3	1
Canada and EU	2	1
UK and USA	-	-
Other or other mix	33	10

Year of publication:

N=332. Percentages are rounded to the nearest full percentage point.

287 (86%) articles were published in the last 20 years, from the year 1997 and onwards. Articles published in the year 1996 or before include a note on the reason for referencing in the thesis.

Year of publication	Frequency	Percentage of 332
2016	1	0
2015	5	2
2014	10	3
2013	13	4
2012	15	5
2011	23	7
2010	16	5
2009	27	8
2008	16	5
2007	25	8
2006	18	5
2005	27	8
2004	15	5
2003	14	4
2002	18	5
2001	8	2

Year of publication	Frequency	Percentage of 332
2000	13	4
1999	13	4
1998	5	2
1997	5	2
1996	8 (spousal carers less likely to relocate relative; challenging behaviours during dental care; definition of functional limitations; co-morbid consequences of eating disability; challenging behaviours with bathing and washing; health complications following a catheter; people with cognitive impairments' preferences for ATs; maintaining use of ATs)	2
1995	5 (physical functional limitations; environmental modifications; cognitive and physical impairments; disabled older people using ATs for mobility; psychological connection to home)	2
1994	2 (definition of dysphagia; disablement model)	1
1993	3 (cognitive impairments; cognitive errors; interventions for informal carers' depression can reduce overload)	1
1992	4 (critique of biomedical model; informal carers' barriers to formal care; skin integrity; simplified dressing wardrobe)	1
1991	6 (Nagi model; COACH algorithms; ethical issues of AT use; informal carers' giving perspectives on home modifications; home modifications can enable people to live at home; Verbrugge investigating human care and ATs with residual disability)	2
1990	3 (feeding and ATS are successful – still same ATs used today; introduction to role captivity; if an informal carer feels that formal care is impersonal it can distress them)	1
1989	-	-
1988	1 (cognitive difficulties with ADL performance)	0
1987	2 (physical impairments with toileting and continence; ethical issues of feeding tubes)	1
1986	2 (definitions of feeding and eating; cognitive errors with ADLs)	1
1985	2 (challenging behaviours when washing; formal care can complement informal care)	1
1984	-	-
1983	1 (barriers to formal care service use)	0
1982	2 (pattern of ADL loss; explaining environmental-press)	1
1981	1 (dining family-style may reduce challenging behaviours - if this was known then why is this still not used in many care homes?)	0
1980	-	-
-	-	-
1975	1 (hierarchical-compensatory model)	0
-	-	-
1973	1 (explaining environmental-press)	0
-	-	-
1965	1 (Nagi model)	0

Focus of literature:

N=332. Percentages are rounded to the nearest full percentage point.

Type	Frequency	Percentage of 332
Peer-reviewed academic papers	301	91
Grey papers	31	9

Type	Frequency	Percentage of 332
Peer-reviewed academic papers:		
Empirical research articles	181	55
Conceptual/theoretical or advice papers, including different types of literature review (e.g. systematic reviews)	91	27
Books or book chapters	29	9
Grey papers:		
Reports	14	4
Charity factsheets	8	2
Policy/governmental papers	5	2
Conference proceedings	3	1
Academic articles in clinician's magazines (advice for clinicians)	1	0

Within peer-reviewed academic papers, N=301

Peer-reviewed academic papers	Frequency	Percentage within 301
Empirical research articles	181	60
Conceptual/theoretical or advice papers, including different types of literature review (e.g. systematic reviews)	91	30
Books or book chapters	29	10

Within grey papers, N=31

Grey papers	Frequency	Percentage within 31
Reports	14	45
Charity factsheets	8	26
Policy/governmental papers	5	16
Conference proceedings	3	10
Academic articles in clinicians magazines (advice for clinicians)	1	3

Within empirical research articles, N=181, focus on population

Population	Frequency	Percentage within 181
People with dementia	40	22
People with cognitive impairment	2	1
Older adults with disability or immobility but no dementia	41	23
Older adults no disability/immobility/dementia	11	6
People with disabilities (no age restriction)	3	2
Informal carers of people with dementia	27	15
Formal carers of people with dementia	5	3
Other types of health and social care staff	5	3
Informal carers of other types of individuals (non-dementia)	5	3
Some sort of mix of populations above, e.g. caring dyads, carers vs. non-carers, residents plus their staff, etc. or general public	42	23

Within empirical research articles, N=181, type of data

Data	Frequency	Percentage within 181
Quantitative	125	69
Qualitative	49	27
Mix of both	7	4

Within empirical research articles, N=181, design type (some articles may be in multiple categories so percentages will not sum to 100%)

Design	Frequency	Percentage within 181
Experimental	6	3
Quasi-experimental	16	9
Non-experimental	164	91

Within empirical research articles, N=181, analysis type (some articles may be in multiple categories so percentages will not sum to 100%)

Analysis	Frequency	Percentage within 181
Cross-sectional	75	41
Longitudinal	69	38
Qualitative e.g. thematic or grounded theory, including observational	45	25
Numerical analysis of qualitative data	3	2

Of literature review and conceptual papers, N=91, focus on population

Population	Frequency	Percentage within 91
People with dementia	44	48
People with cognitive impairment	3	3
Older adults with disability or immobility but no dementia	16	18
Older adults no disability/immobility/dementia	7	8
People with disabilities (no age restriction)	7	8
Informal carers of people with dementia	1	1
Formal carers of people with dementia	-	-
Other types of health and social care staff	1	1
Informal carers of other types of individuals (non-dementia)	-	-
Some sort of mix of populations above, e.g. caring dyads, carers vs. non-carers, residents plus their staff, etc. or general public	5	5
Technologies	7	8

Of literature review and conceptual papers, N=91, described literature search strategy comprehensively: 18 (20%).

Of books and book chapters, N=29, focus on population

Population	Frequency	Population
People with dementia	6	21
People with cognitive impairment	-	-
Older adults with disability or immobility but no dementia	5	17
Older adults no disability/immobility/dementia	3	10
People with disabilities (no age restriction)	6	21
Informal carers of people with dementia	1	3
Formal carers of people with dementia	-	-
Other types of health and social care staff	1	3
Informal carers of other types of individuals (non-dementia)	2	7
Some sort of mix of populations above, e.g. caring dyads, carers vs. non-carers, residents plus their staff, etc. or general public	3	10
Technologies	2	7

Appendix 3: ELSA analysis

Waves of ELSA

Wave	Years data were collected	Consisted of	Total number of participants in dataset	Fieldwork individual response rate	Data collected on ATs
Wave 1	2002-2003	Main interview	12,099	67% ('Cohort 1')	Use of: cane or walking stick; walking frame or walker; manual wheelchair; electric wheelchair; buggy or scooter; special eating utensils; personal alarm
Wave 2	2004-2005	Main interview Nurse visit	9,432 7,666	82% Cohort 1	Use of: cane or walking stick; walking frame or walker; manual wheelchair; electric wheelchair; buggy or scooter; special eating utensils; personal alarm; elbow crutches
Wave 3	2006-2007	Main interview Life history	9,771 7,855	73% Cohort 1; 74% for refreshment sample members ('Cohort 3')	Use of: cane or walking stick; walking frame or walker; manual wheelchair; electric wheelchair; buggy or scooter; special eating utensils; personal alarm; elbow crutches
Wave 4	2008-2009	Main interview Nurse visit	11,050 8,643	74% Cohort 1; 78% Cohort 3; 63% for refreshment sample members ('Cohort 4')	Use of: cane or walking stick; walking frame or walker; manual wheelchair; electric wheelchair; buggy or scooter; special eating utensils; personal alarm; elbow crutches
Wave 5	2010-2011	Main interview Risk module	10,274 1,060	78% Cohort 1; 77% Cohort 3; 86% Cohort 4	Use of: cane or walking stick; walking frame or walker; manual wheelchair; electric wheelchair; buggy or scooter; special eating utensils; personal alarm; elbow crutches
Wave 6	2012-2013	Main interview Nurse visit	10,601 8,054	85% Cohort 1; 82% Cohort 3; 83% Cohort 4; 55% for refreshment sample members ('Cohort 6')	Use of: cane or walking stick; walking frame or walker; manual wheelchair; electric wheelchair; buggy or scooter; special eating utensils; personal alarm; elbow crutches
Wave 7	2014-2015	Main interview	Dataset and Wave 7 Technical Report not accessible at time of thesis submission		

Sources: (Batty et al., 2014, Blake et al., 2015, Bridges et al., 2015, Cheshire et al., 2012, Scholes et al., 2008, Scholes et al., 2009, Steptoe et al., 2013, Taylor et al., 2007, The Institute for Fiscal Studies, 2011a)

Creation of new dataset variables

Original contributing variables	New derived variable name	New variable code
Walking stick or cane, walker, manual wheelchair, electric wheelchair, buggy or scooter, elbow crutches	Mobility-related ATs	Uses none of these Uses at least one of these
Orientation Immediate recall Delayed recall	Cognitive function index (quintiles)	1 (lowest cognitive function) 2 3 4 5 (highest cognitive function)
ADLs: dressing, washing, bathing, getting in and out of bed, eating, using the toilet	ADL difficulty	No ADL difficulty Difficulty with 1-3 ADLs Difficulty with 4-6 ADLs
IADLs: using a map, preparing food, shopping, using the telephone, taking medication, doing housework or gardening, managing money	IADL difficulty	No IADL difficulty Difficulty with 1-3 IADLs Difficulty with 4-7 IADLs
Glaucoma, diabetic eye disease, macular degeneration, cataracts	Poor eye health	Has none of these eye conditions Has at least one eye condition
High blood pressure	High blood pressure	Does not have high blood pressure Has high blood pressure
Stroke	Stroke	Has not had a stroke Has had a stroke
Angina, congestive heart failure, heart murmur, abnormal heart rhythm, high cholesterol, heart attack	Other cardiovascular condition	Has none of these CVD conditions Has at least one CVD condition
Diabetes	Diabetes	Does not have diabetes Has diabetes
Lung disease, asthma	Lung disease and asthma	Has neither lung disease or asthma Has lung disease and/or asthma
Arthritis	Arthritis	Does not have arthritis Has arthritis
If incontinence lasted more than 1 month	Incontinence	No incontinence Has incontinence
Depressive symptoms 1-8	Depressive symptoms	Has 0-3 depressive symptoms Has 4-8 depressive symptoms
Whether they ever fell seriously enough to require medical treatment	Fall with injury	Has not fell and caused injury Has fell and caused injury
Sex	Sex (unchanged)	Male Female
Age	Age category	65-74 years old 75-84 years old 85-90+ years old
Wealth	Wealth index (quintiles)	1 (lowest wealth) 2 3 4 5 (highest wealth)

Appendix 4: Study design - materials and instruments

SCREC ethical approval confirmation



Social Care REC

An NRES Research Ethics Committee

09 October 2012

Miss Suzanne J Hardy
Institute of Gerontology
Department of Social Science, Health and Medicine
King's College London
King's Building, The Strand, London
WC2R 2LS

Dear Ms Hardy

Study title: The role of Assistive Technology for personal-care in enabling families to care for relatives with dementia in their location of choice

IRAS Project Number: 100731

REC reference: 12/IEC08/0025

Ethical opinion: Favourable

Thank you for your letter of 26 September 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC during the week commencing 08 October 2012. A list of the Sub-Committee members is attached.

The Committee noted that this is a full and considered response which addressed both Mental Capacity Act and Data Protection Act issues.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

The Committee would like to offer advice which is not part of the ethical decision. Where an assumption of capacity can reasonably be made there is no requirement to assess capacity.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of Section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity-to-consent to taking part in the project.

Site-Specific Assessment

The REC decided that the research did not require Site-Specific Assessment at non-NHS sites as it involves no clinical intervention and all the study procedures at sites would be undertaken by the Chief Investigator's team.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Guidance on Research Governance approval is available from the Department of Health supported Research Governance Framework: Resource Pack for Social Care (2nd ed, April 2010) London, which can be found at: <http://www.researchregister.org.uk/files/RGFGuidancepack2010.pdf>

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You must notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		02 May 2012
Covering Letter		26 September 2012
Evidence of insurance or indemnity	ANONYMISED	22 September 2011

Investigator CV	Miss Suzanne Hardy	
Investigator CV	Dr Karen Glaser	02 February 2012
Investigator CV	Professor Anthea Tinker	
Letter from Sponsor	Offer letter to Suzanne Hardy PhD ESRC CASE	15 July 2010
Other: Letter from Funder - Letter of confirmation CASE Studentship 2010		26 April 2010
Other: Scan of CRB clearance records		
Other: Interview Topics - family and friends - Stage Two	1	02 February 2012
Other: Interview Topics - keyworkers - Stage Two	1	02 February 2012
Other: Pilot study low-risk approval record		
Other: Stage One Consent Procedure and summary Flowchart (Appendix I)	1	05 September 2012
Other: Pre Data Collection Family Letter (Appendix II)	1	13 August 2012
Other: Resident Capacity Form (Appendix IV)	1	14 June 2012
Other: Supported Decision-making Form (Appendix V)	1	14 June 2012
Other: Family Courtesy Letter	1	14 June 2012
Other: Personal Consultee Letter (Appendix IX)	1	13 August 2012
Other: Personal Consultee Form (Appendix X)	1	14 June 2012
Other: Procedure for Those who Become Distressed (Appendix XI)	1	13 June 2012
Other: Procedure for breaching confidentiality (Appendix XII)	1	13 June 2012
Other: Family and Friends' Interview Invitation Letter	2	13 June 2012
Other: Family and Friends' Study Form	2	13 June 2012
Other: Keyworker Interview Invitation Letter (Appendix XVI)	2	13 June 2012
Other: Keyworker Study Form (Appendix XVII)	2	13 June 2012
Other: Stage One mapping framework (Appendix XIX)	2	13 June 2012
Other: Research Protocol (Appendix XXI)	2	13 August 2012
Other: Protocol summary and Data Collection Flowchart (Appendix	2	13 August 2012
Participant Consent Form: Interviewee (Appendix XX)	2	13 June 2012
Participant Information Sheet: Resident (Appendix VI)	2	12 September 2012
Participant Information Sheet: Family and Friends' (Appendix	2	13 June 2012
Participant Information Sheet: Keyworker (Appendix XVII)	2	13 June 2012
REC application	10731/31985 9/27/227	02 May 2012

Referees or other scientific critique report	Confirmation CASE Studentship 2010 letter	26 April 2010
Response to Request for Further Information		
Summary/Synopsis	1	02 December 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the Social Care REC website – www.screc.org.uk and look at the “*After Ethical Review Section*” for details of further requirements. The attached document “*After Ethical Review – Guidance for Sponsors and Investigators*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

Feedback to the Social Care REC

The Committee would welcome your views on the service you have received from the Social Care REC and the application procedure. You can do this anonymously by completing our feedback form at: www.screc.org.uk/feedback.asp

Research register for social care

The research should now be registered on the Research Register for Social Care - visit www.researchregister.org.uk to do so.

12/IEC08/0025

Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Should you require clarification of any issues arising from this correspondence please contact the Committee Co-ordinator, Barbara Cuddon.

Yours sincerely



Professor David Stanley
Chair

Scan of CRB check

Enhanced Disclosure		disclosure	
Page 1 of 2		Disclosure Number	001320235067
		Date of Issue:	19 APRIL 2011
Applicant Personal Details		Employment Details	
Surname:	HARDY	Position applied for:	RESEARCH POST
Forename(s):	SUZANNE JANE	Name of Employer:	ANONYMISED
Other Names:	NONE DECLARED	Countersignatory Details	
Date of Birth:	29 DECEMBER 1984	Registered Person/Body:	ANONYMISED
Place of Birth:	DERBY	Countersignatory:	ANONYMISED
Gender:	FEMALE		
Police Records of Convictions, Cautions, Reprimands and Warnings			
NONE RECORDED			
Information from the list held under Section 142 of the Education Act 2002			
NONE RECORDED			
ISA Children's Barred List information			
NONE RECORDED			
ISA Vulnerable Adults' Barred List information			
NONE RECORDED			
Other relevant information disclosed at the Chief Police Officer(s) discretion			
NONE RECORDED			
Enhanced Disclosure			
This document is an Enhanced Criminal Record Certificate within the meaning of sections 113B and 116 of the Police Act 1997.			
THIS DISCLOSURE IS NOT EVIDENCE OF IDENTITY		Continued on page 2	
CRB PO Box 165, Liverpool, L69 3JD Helpline: 0870 90 90 844		© Crown Copyright 2011	

Research Protocol Summary and Data Collection Flowcharts

The role of Assistive Technology for ADLs in enabling families to care for relatives with dementia in their location of choice

Purpose

This project aims to investigate whether, and if so, how, Assistive Technologies (ATs) can be used to assist people with dementia to conduct Activities of Daily Living (ADLs) (for example hygiene matters such as washing, toileting and continence, along with grooming and feeding oneself), and to examine the role ATs can play in enabling people caring for a relative with dementia to make preferred choices in their location of care. The UK's National Dementia Strategy (Department of Health, 2009) objectives include; i) ensuring that people with dementia live well (whether in their own home or in a care home) and ii) a call for more research on the role of AT to address the needs of people with dementia and their carers. This project will investigate the perceptions of formal and family carers of people with dementia on ATs for ADLs. The project will explore the following Research Questions:

1. What cognitive and physical difficulties do people with dementia have performing ADLs whilst they reside in the community?
2. What types of ATs may people with dementia and their informal and formal carers use to assist their performance of ADLs whilst living at home?
3. What are informal carers' preferences, barriers and facilitators with respect to the use of such ATs by people with dementia when they live at home? What are the routes to obtaining these types of ATs? How do families and formal services inter-relate with regards to assistance for ADLs and potential and actual AT use?
4. What is the tipping point for a decision for a person with dementia to relocate to a care home? Is this ever related to AT use or non-use for ADLs?
5. Does a person with dementia's performance of ADLs alter after relocation to a care home? How do ATs for ADLs used in care home settings enhance the late-life care of residents, and encourage families' connections with residents and care home staff?

Method

This project will use an in-depth multiple contrasting case study design (Yin, 2003). Each case will consist of a care home resident with a clinical diagnosis of dementia, along with their key informants: their formal carer (their keyworker at the care home) and their informal carers (family members and friends who assisted in caring activities before they relocated to the care home). Multiple sources of inquiry will be used to create each case; using data mapped from the resident's care record held at the care home (Stage One) and interviews with their case informants (Stage Two). For Stage One, when included in the care record, data concerning: demographics, health issues including the type and time of the dementia diagnosis, the circumstances of care whilst the resident was living at home including whether they received formal services and/or used ATs, the circumstances around the decision for institutionalisation, and current ADL assistance and AT use at the care home will be mapped.

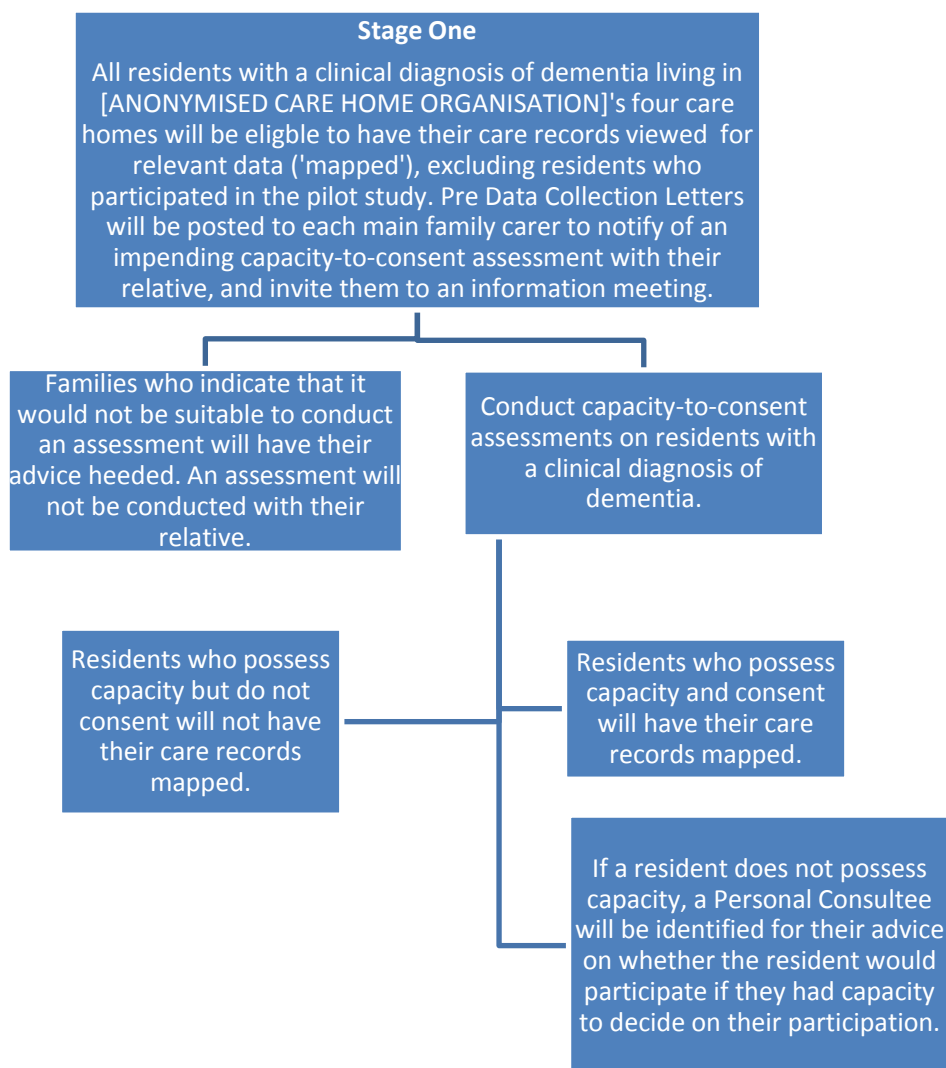
Approximately 15-20 residents will be selected from the 68 for further investigation in Stage Two. Criteria used for case selection will include: their care home location, their keyworker, the type of dementia they have been diagnosed with and its severity, their age, gender, the length of time they have been in the care home, the composition of family members including who is listed as the main carer, and, if such history is in the care records, whether it is known if they used ATs before relocating to the care home.

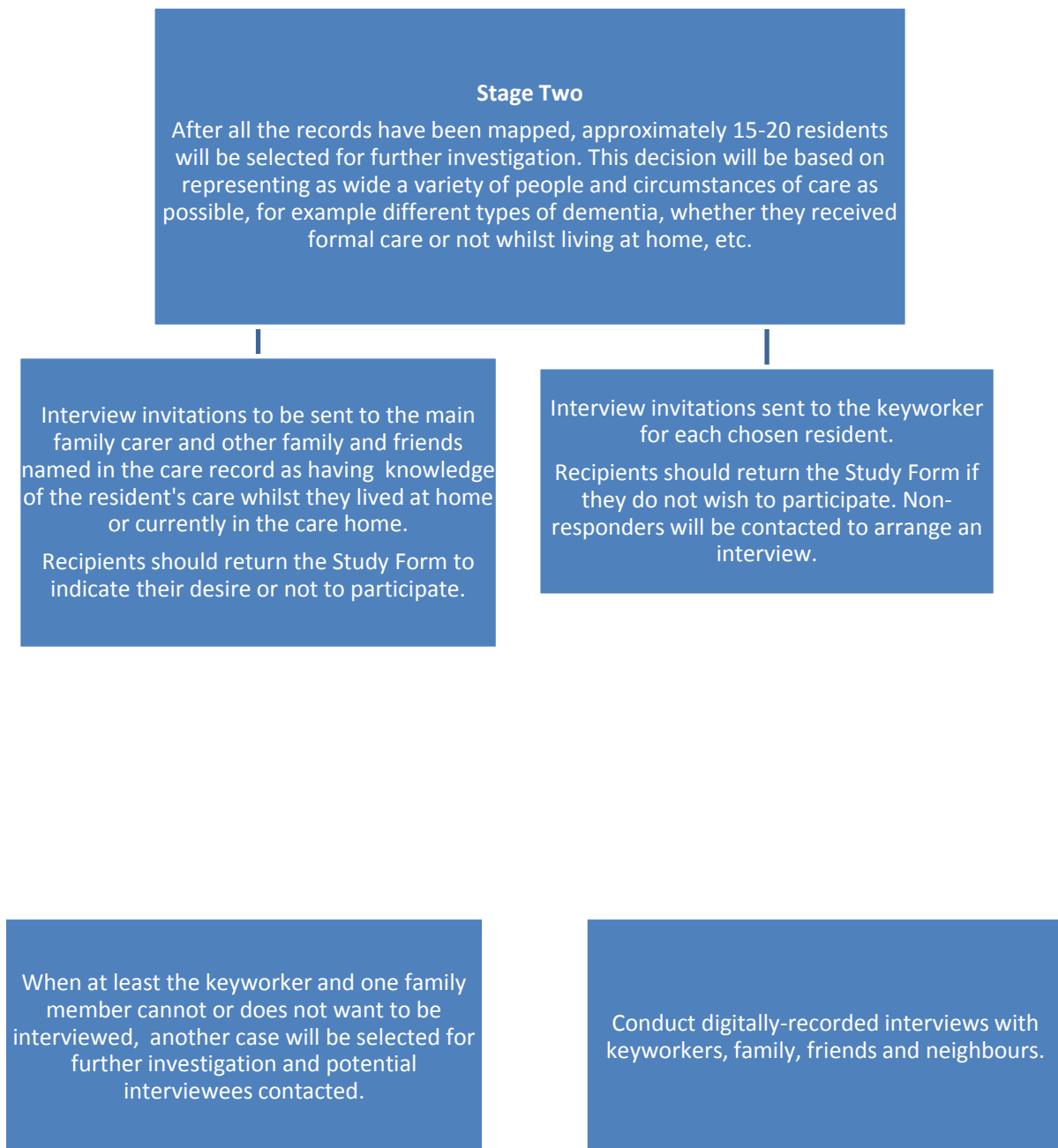
Type of participant

Participants will consist of the resident with dementia and their Personal Consultee (if necessary) for Stage One, keyworkers at the care homes and familial carers including family members, neighbours and friends of current residents with dementia for Stage Two.

Location of research

[ANONYMISED CARE HOME ORGANISATION] will provide access to its four care homes. [ANONYMISED CARE HOME ORGANISATION] is dedicated to advancing the standards of excellence in the residential care of older people. These care homes provide: dementia, nursing, residential and day care for older adults. All care home residents with a clinical diagnosis of dementia, excluding participants in the pilot study, are eligible to have their care record mapped for Stage One. The researcher has a CRB enhancement disclosure with the care home organisation [ANONYMISED CARE HOME ORGANISATION], has volunteer status and is covered by the organisation's indemnity insurance while at the care homes.





Procedure for Breaking Confidentiality

Confidentiality is central to keeping information provided within a professional relationship secure and secret from others. In the context of this project, confidentiality principles apply to the data mapped from the care records in Stage One and from participant interviews in Stage Two. These principles ensure maintained trust between the research team (formed by the Chief Investigator and supervisory committee) and the participant.

It is conceivable that during care mapping or interviews, data may be uncovered or information may be provided that necessitates a breach of confidentiality. Qualifying information is that which indicates that the resident with dementia, their family member or friend or another is at risk of harm. The Chief Investigator must then act under a duty to warn or protect others under risk.

Where the Chief Investigator detects the disclosure of potential qualifying information, they will discuss this with the participant (resident or Personal Consultee if during Stage One, interviewee if in Stage Two), gaining clarification if necessary. Where it is clear that the information is eligible for disclosure, they will notify the participant that they will be obliged to breach the confidentiality agreement and disclose the information to appropriate parties. This procedure will still occur even if the participant decides to withdraw their data from the study and no longer participate.

The Chief Investigator will first discuss with the supervisory committee what has been disclosed in order to decide to whom the information should be passed. Potential recipients include the care home manager, the dementia training specialist at the care home, local social services or the police.

To inform potential interview participants of this procedure the following statement is provided on the Information Sheet for family and friends and keyworkers; 'Everything you say in the interview is confidential unless you report something that indicates you or someone else is at risk of harm. The interviewer will discuss this issue with you before telling anyone else'. Potential interview participants will receive the Information Sheet both in an Interview Invitation Pack and again before the interview begins. They will then freely sign a Consent Form that confirms they understand the information they have been given.



Reference

This is your report, generated by the responses you gave while completing the AMCAT. You may want to enter a reference in the box below to remind you of the particular assessment it applied to. We hope it helps you to reflect on the assessment that you did and informs your future practice. For further information, links to useful resources, and to share your experiences of assessing capacity please return to the assessing mental capacity website at <http://www.assessingmentalcapacity.org.uk>

Q: What is your relation to the person whose capacity was being assessed?

“Researcher” You entered this response manually. The AMCAT is an automated tool so we are not able to comment on this element of your response.

Q: Did the person you assessed have one or more of the following?

You were assessing the capacity of a person with dementia. The Mental Capacity Act (MCA) only applies to people who have an impairment or disturbance of the mind or brain, such as dementia. However, you should only start an assessment of the person’s capacity if their dementia is affecting their capacity to make a specific decision when they need to.

Q: Why did you do the assessment?

Your assessment was prompted by the person’s disability, history, diagnosis or illness. According to the MCA an assessment of capacity should never be done for these reasons alone, although they might be one of several factors indicating the person may lack capacity. An assessment of capacity should only be made when a person with some form of mental impairment or disturbance of the mind is having a problem making a particular decision at a particular time.

Q: How long did you have to assess the person’s capacity before the decision had to be made or action taken?

You said that you had more than a week to carry out the assessment. The issue of capacity relates to a specific decision at the time that it needs to be made. The time an assessment takes will be determined by the urgency and importance of the decision under consideration, the ease of access to relevant information or the right support for the person being assessed and the availability of specialist help (from a psychologist, for example) where it is required. The principles of good practice in assessing capacity apply however long the assessment takes.

Q: Before starting the assessment did you think that the person was able to make the decision?

Before starting the assessment you were not sure if the person was capable of making the decision. Unless the person was clearly unconscious at the time you should always start off by assuming a person has the capacity to make a decision unless it is proven otherwise, in keeping with the first

principle of the Act. However, an assessment is triggered because you have 'reasonable belief' that the person may have difficulty making the decision and there may therefore have been factors that gave you the belief that the person may lack capacity and you therefore decided to do an assessment. However, until the assessment is complete, you should continue to assume that the person has capacity to make the decision in question.

Q: What was the decision about?

You carried out an assessment of a person's capacity to make a decision about taking part in research.

Q: Was it relevant to involve someone who could tell you how best to communicate with the person?

By involving someone who could tell you how best to communicate with the person, you satisfied the second principle of the Act (and both Chapters 3 and 4 of the Code of Practice). This says you should always try to involve people who know the person well to find out how best to communicate with the person and involve them in the assessment if appropriate.

Q: Was it relevant to have someone to support the person to make the decision – such as a relative, friend or advocate?

You made sure there was someone to support the person make the decision. When assessing capacity you should consider whether the person might benefit from having another person present. But you should also remember to respect a person's right to confidentiality.

Q: Did you ensure the person had all the relevant information to make the decision?

You made sure that the person had all relevant information in order to make the decision. This is in line with the second statutory principle of the MCA which says that a person is not to be treated as unable to make a decision until all practicable steps to help them do so have been taken without success. This includes providing them with relevant information. When assessing capacity, it is good practice to make sure that you understand the nature and effect of the decision to be made yourself. To do this you may need access to relevant documents and background information about the person.

Q: Did you explain the information in a way that was easy for the person to understand?

You explained the information in a way that was easy for the person to understand. The MCA says that a person is assumed to have capacity unless it is established otherwise and that all practicable steps must be taken to help them make a decision. A crucial part of this is ensuring that you explain the information in a way that is easy for the person to understand.

Q: Was it relevant to check if there were any cultural, ethnic or religious factors which should have been taken into account?

You checked if there were any cultural, ethnic or religious factors which might have had a bearing on the person. This meets the requirement set out in chapter 3 of the Code of Practice about the need to be aware such factors that may shape the persons way of thinking, behaviour and communication so you should always take such factors into account.

Q: Did you take any other practicable steps to put the person at their ease to make the decision?

You took extra steps to put the person at ease. This is good practice when assessing capacity as you should always make the person feel at ease; this might include considering an appropriate

time of day to assess the person and ensuring the location is suitable. This is covered by chapters 3 and 4 of the code of practice.

Q: Was it relevant to ask for specialist advice about the persons' capacity?

You thought it was relevant to ask for specialist advice and you did this. Chapter 3 of the Code of Practice states that if you are assessing a person with specific communication difficulties you may require specialist help and Chapter 4 of the Code of Practice states that anyone assessing capacity may need to get a professional opinion. If you believe that specialist advice is relevant then you should always seek it – this may be particularly relevant for more complex or serious decisions such as consent for medical treatment or a significant change in someone's care arrangements.

Q: Were you satisfied that the person could understand the nature of the decision?

You judged that the person could not understand the nature of the decision. Before you assess a person's capacity, you must find out whether or not they understand the nature of the decision being made. In doing so, you should satisfy yourself that the person has access to any relevant documents or background information

Q: Were you satisfied the person understood why the decision needed to be made at that time?

You thought the person could not understand the reason why the decision was needed. You must ensure that a person has all the relevant information before assessing their capacity. Relevant information includes the reasons why the decision is needed. This is covered by chapter 4 of the Code of Practice.

Q: Were you satisfied that the person could understand the likely effects of deciding one way or another?

The first stage of assessing capacity is whether a person understands the consequences of making the decision one way or another. In this assessment you thought that the person could not understand the likely effects of deciding one way or another.

Q: Were you satisfied that the person could retain the information about the decision long enough to use it to make the decision (even if this was only for a short time)?

The second stage of assessing capacity is whether a person hold the information in their mind long enough (if only for a short time) to make an effective decision. In this assessment, you thought the person could not retain information about the decision long enough to use it.

Q: Were you satisfied the person could use or weigh up this information (e.g. understand the pros and cons) as part of the decision making process?

The third stage of assessing capacity is whether a person can use or weigh up information in order to make a decision. In this assessment you found the person could not use or weigh up the information available to them as part of the decision-making process.

Q: Could the person communicate their decision in any way (i.e. verbally, non-verbally or in their behaviour or actions)?

The fourth stage of assessing capacity is that the person can communicate their decision. In this assessment you said that the person could not communicate their decision. Remember that if a person can communicate their decision in any way then they must be treated as able to make a decision.

Q: What did you decide about the person's capacity?

You assessed the person as not having capacity to make the decision at this time. This means you established that the person was unable to do one or more of the following: i) understood the information relevant to that decision, including understanding the likely consequences of it, ii) retain the information, iii) weigh the information as part of the process of making the decision, and iv) communicate their decision, whether by talking, using sign language or any other means. Remember that every effort should be made to find ways of communicating with someone before deciding that they lack the capacity to make a decision based solely on their inability to communicate. Very few people will lack capacity on this ground alone. Your assessment must be made on the balance of probabilities – that it is more likely than not that the person lacks capacity – and you should be able to show why you have come to that conclusion.

Q: How did you decide about the person's decision-making capacity?

You reached a decision about the person's capacity on the balance of probability having looked at all the relevant information. This is good practice according to Chapter 4 of the Code of Practice.

Q: Could the decision have been delayed until the person could make it themselves?

You said that it unclear if it was possible to delay the decision until the person could make it themselves. The second statutory principle of the MCA is that a person must not be treated as unable to take a decision unless all practicable steps to help them have been taken. If it is practical to delay the decision until the person could make it for themselves then you should do this.

Q: How did you record your assessment?

Your assessment was recorded on a standard form specifically designed for this purpose. It is good practice, especially for paid care workers, to keep a record of the steps taken in assessing someone's capacity (perhaps in a person's care plan or records) to show they had 'reasonable belief' that the person lacked capacity. For more significant decisions it would be appropriate to record assessments formally. It is good practice for people with professional roles to carry out a proper assessment of a person's capacity to make particular decisions and to record the findings in the relevant professional records. If you are a doctor or healthcare professional proposing treatment and carrying out an assessment of the person's capacity-to-consent you should record it in the patient's clinical notes. Remember that although someone else recorded your assessment, as the decision-maker you retain the responsibility for it. Sections 4.60-4.62 of the Code of Practice give guidance on who should keep a record of assessments.

Procedure for Those who Become Distressed

This project will involve interviews with keyworkers, family and friends of care home residents with a clinical diagnosis of dementia. The interviews will be conducted by the Chief Investigator ('interviewer') of the project and recorded on a digital recorder.

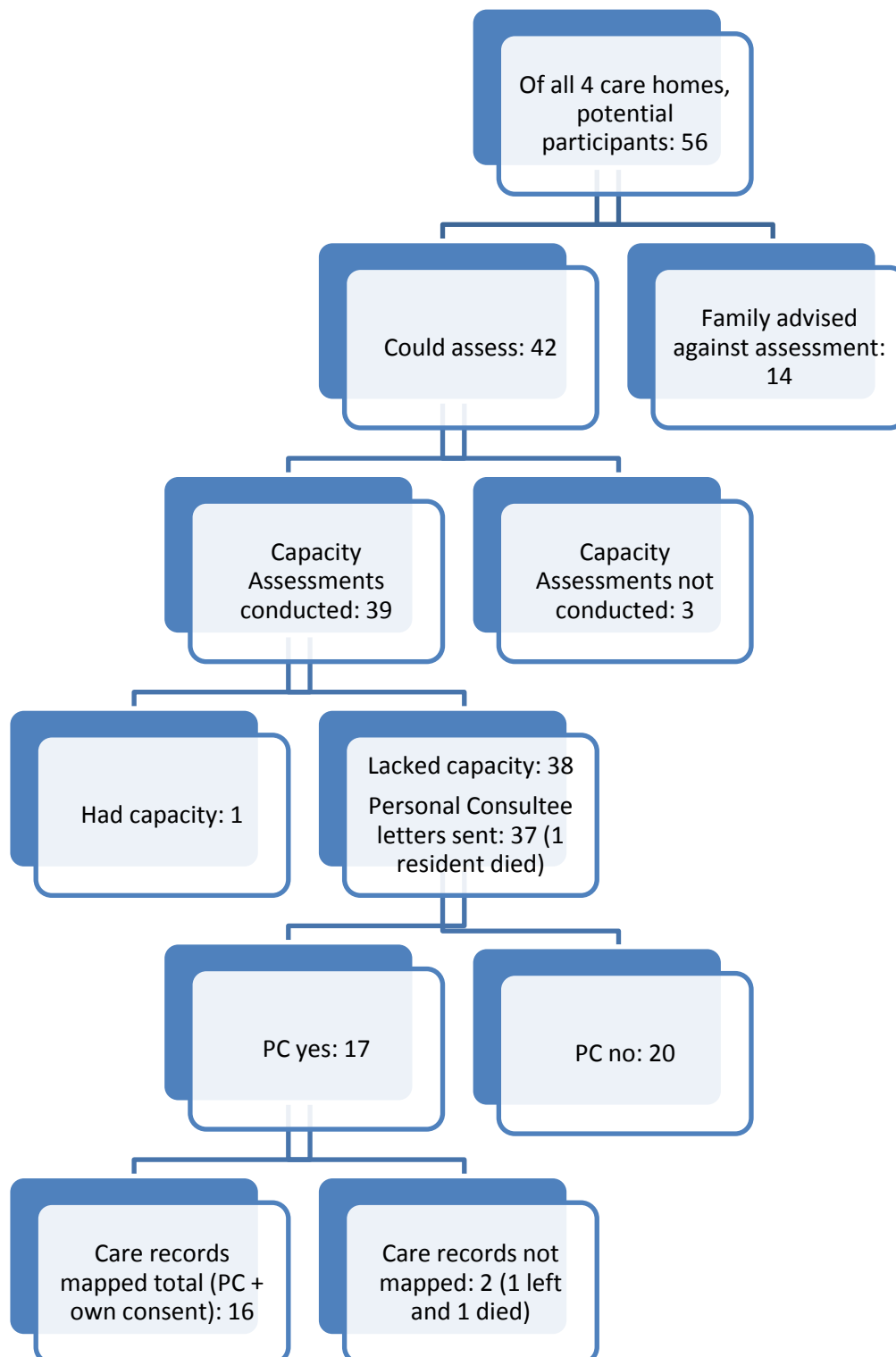
It is conceivable that during the interview participants may become upset or distressed due to the nature of the interview topics, the question they are answering, the experiences they are remembering and describing and the overall situation. Where this occurs, the interviewer will ask the participant if they would like to halt the interview and will pause the digital recording. The participant will be given as much time as they need to become composed and there will be water and tissues on the interview table for participants to use if necessary. The interviewer and participant may or may not continue a discussion, unrecorded, or as the participant wishes, about the situation. At an appropriate time, the interviewer will reiterate the following three options to the participant: a) they may return to the interview (the semi-structured nature of the topics will enable them to talk about why they are upset on recording if they so wish); b) they can stop the interview; or c) they can stop the interview and withdraw the data they have provided so far. Where a) or b) occur, participants will be reminded that they will be able to withdraw their data any time until their interview has been transcribed.

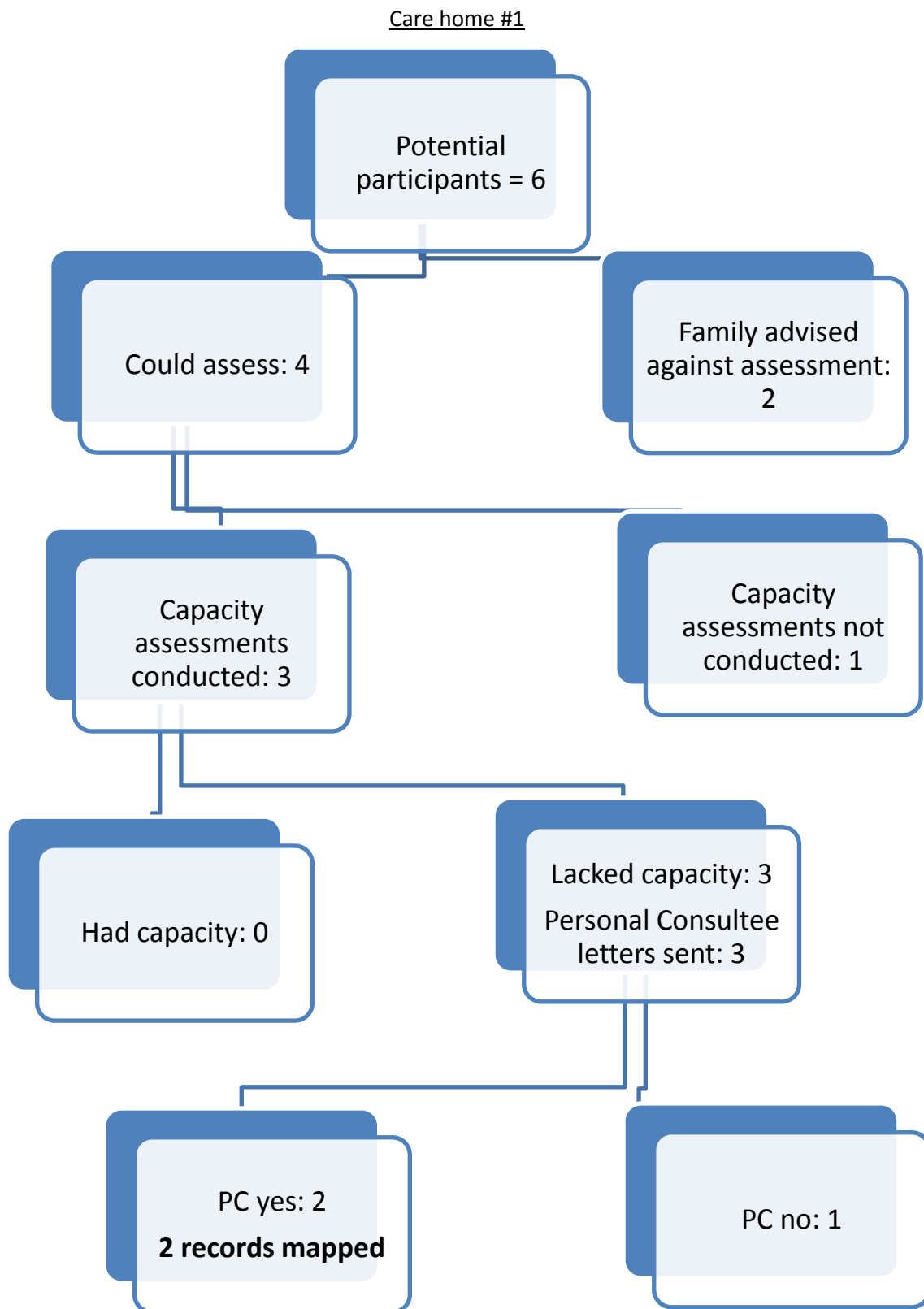
To inform potential interview participants of this procedure the following statement is provided on the Information Sheet for family and friends and for keyworkers; 'It is possible that you may find answering some of the questions distressing or upsetting. If this occurs you may wish to pause or stop the interview. You could then: terminate and withdraw your data (the interview recording would be deleted), terminate the interview and allow the interview recording until that point to be used in the research, or carry on with the interview when you are ready'. Potential interview participants will receive the Information Sheet both in an Interview Invitation Pack and again before the interview begins. They will then freely sign an Interviewee Consent Form that confirms they understand the information they have been given.

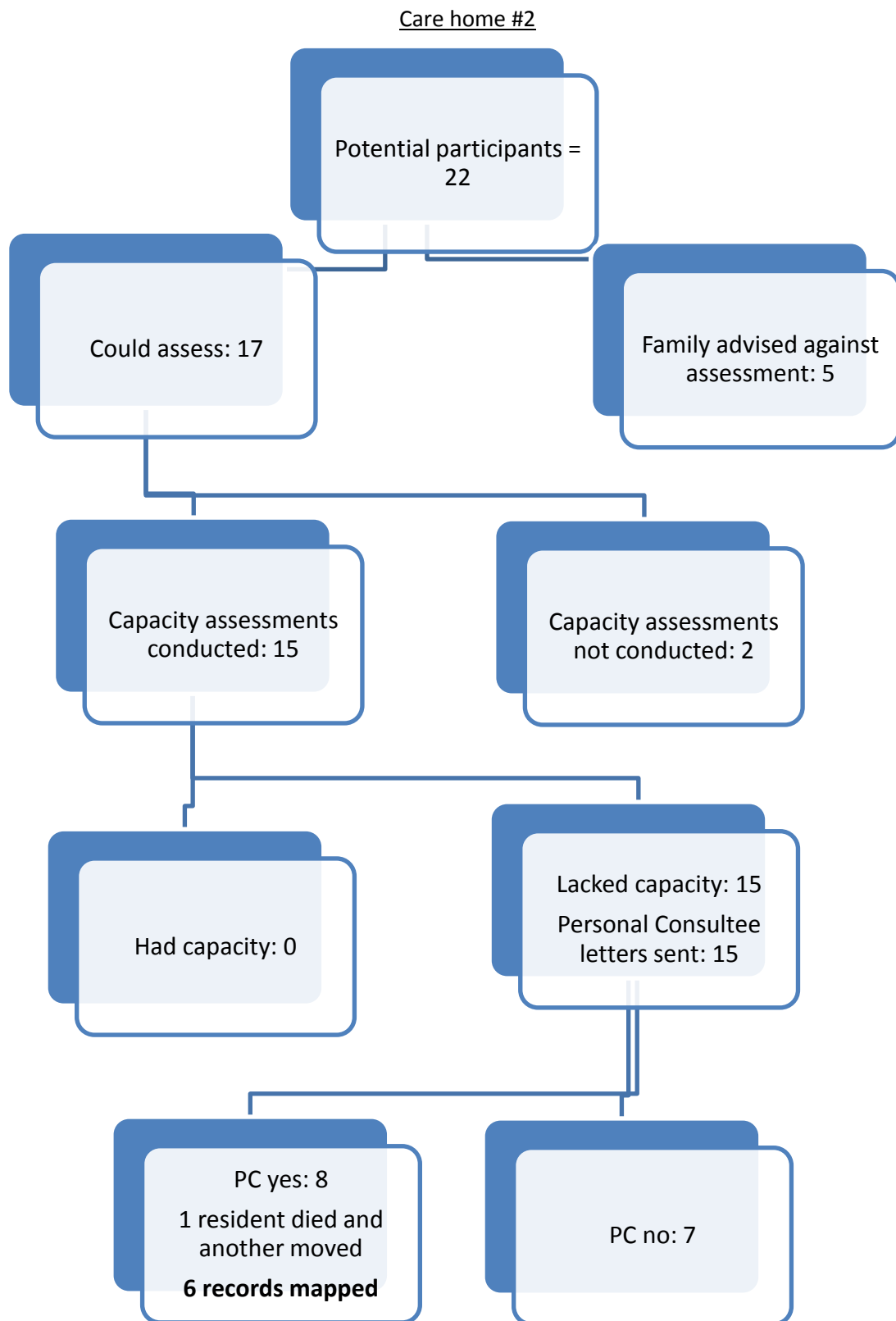
Feedback to the supervisory committee will only be given by the Chief Investigator if necessary, e.g. to notify that a resident will now not be contribute to a Stage Two case study if the participant decides to withdraw their information. This does not break the confidentiality agreement as the agreement is with the whole research team.

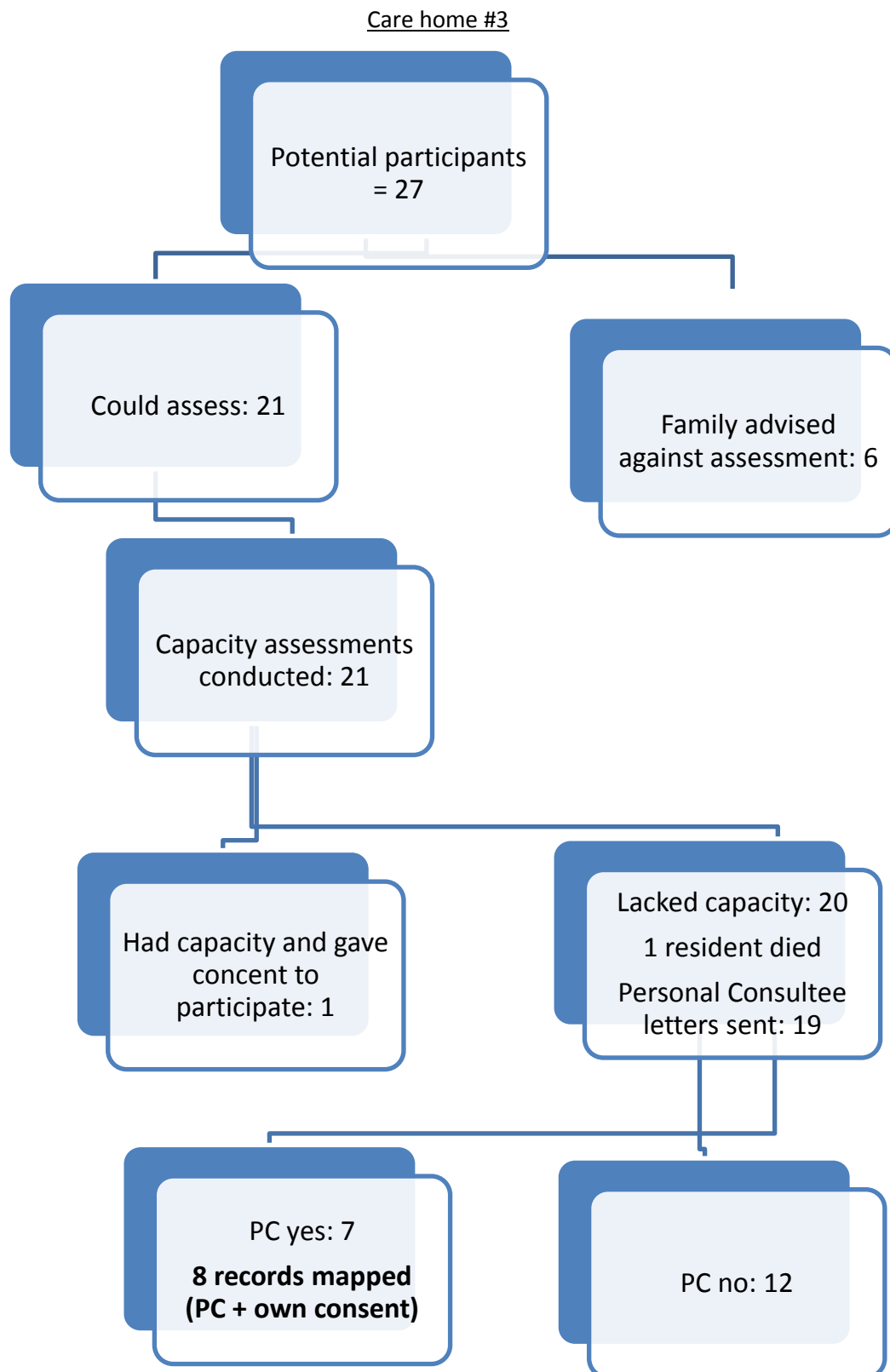
Flowcharts of Stage One participant numbers

Final numbers









Care home #4

Potential participants = 1

After discussion and initial agreement, the family got in touch and indicated they would prefer for the capacity assessment not to occur

0 records mapped

Care mapping framework

(Spaces are condensed to fit onto one page)

Resident:

Baseline			
Gender		Year of birth	
Marital status			
Diagnosis		Date of diagnosis	
Estimate of severity		Medication use	
Care arrangements before relocation			
Where they lived and who with			
Informal carers, family and friends			
What informal care was provided			
Did they ever go to respite, day care, etc.?			
Formal services coming to their house? Who (which Local Authority)? How often?			
Hospital admission			
Problems with daily living tasks			
AT use			
Care arrangements after relocation			
Date of relocation		Keyworker	
Why relocation occurred			
Family and friends listed as contacts or visitors			
Independent enough to leave the care home alone or with family?			
Problems with daily living tasks			
Care needs, anything specialist			
Assistive Technology used to help with these tasks			
Other			

Pre Data Collection Family Letter and Pre Data Collection Form



Room K4U.13
Institute of Gerontology
Department of Social Science, Health
and Medicine
King's College London
King's Building
The Strand
London
WC2R 2LS

[EMAIL ADDRESS]
[OFFICE NUMBER]
[MOBILE NUMBER]

[DATE]

Dear Sir/Madam

This letter is to notify you of a research project being undertaken at [ANONYMISED CARE HOME ORGANISATION] care homes in accordance with King's College London. The letter will provide information about the project, the stages of data collection, notify you of a capacity-to-consent assessment to be conducted on your relative before data collection begins, enable you to be present at this assessment if you wish, enable you to request that your relative does not have an assessment if you wish, and invite you to an information meeting at the care home about the project.

The research project

We are researchers at King's College London collaborating with [ANONYMISED CARE HOME ORGANISATION] in order to find out how the use of Assistive Technologies (ATs) for personal-care activities (that is, activities such as washing, dressing and eating) may play a role in enabling those families caring for a relative with a clinical diagnosis of dementia to care for them in their location of choice. This research is important because even though studies have shown that ATs play an important role in personal-care, and may act to delay admission into more intensive services, little research has investigated this issue among those with a cognitive impairment. The national Social Care Research Ethics Committee has granted ethical approval.

In collaboration with [ANONYMISED CARE HOME ORGANISATION] we will be working in [ANONYMISED CARE HOME ORGANISATION] care homes in order to identify residents with a clinical diagnosis of dementia. In the first stage of the project we will be utilising the data held in the care records of [ANONYMISED CARE HOME ORGANISATION] residents with a clinical diagnosis of dementia to create 'care maps' using relevant information about their past and current care arrangements, their reason for relocation to the care home, the diagnosis of dementia, past and current use of AT, and finally to determine their keyworker at the care home, their main informal carer (you), and any other family members and friends who have been involved in care both prior to and following relocation to the care home. Once the 'care maps' have been created, we will be inviting some families and keyworkers to participate in interviews. These interviews will focus on the ATs that the resident used to help with their personal-care before they resided at the care home (i.e. in their own home or whilst in hospital, for example) and current technology use in the care home. This means that you may be contacted at a later date, and if so further information about the study will be given.

Capacity-to-consent assessments

In accordance with the Mental Capacity Act 2005 we must conduct a capacity-to-consent for participation in the project on all residents involved. Therefore we will be conducting a capacity-to-consent assessment with your relative to determine if they can make a decision on whether or not they would like to be in the project. Their participation concerns only permission for their care record to be viewed and potentially for their care circumstances and use of ATs to be the subject of interviews with their informal (family) and formal (keyworker) carers. No other action will be required of them for participation in the research project. Assessments such as this are a normal part of dementia care. Every time a new decision must be made about your relative, a change in medication or care plan for example, a capacity-to-consent assessment is carried out. This is because it must never be assumed that someone lacks capacity to make a decision, even if they have lacked capacity in the past. Each assessment is about a particular and specific decision. The assessment will be carried out by the project researcher, Suzanne Hardy. She will introduce herself to your relative and explain that she is conducting a study at [ANONYMISED CARE HOME ORGANISATION] care homes. She will explain that she would like to view their care record and may wish to ask their family members and keyworker to talk to her about perceptions of their care and any technology they may use or did in the past. The assessment concerns whether your relative can remember that information, understand it, and weigh up the potential consequences in their mind (there will be no adverse consequences). Your relative will not be interviewed about their care or use of technology. Contact details are provided above if you have concerns or questions.

Assessment result

If residents are assessed to possess capacity-to-consent, they will make a decision on their participation in the project.

Residents may be assessed to not possess capacity-to-consent on this decision (NB the capacity-to-consent assessment refers only and specifically to the decision of participation in the research (permission to view their care record), it does not relate to their capacity to make any other decision). In such circumstances we will contact you, as a person interested in the welfare of your relative. This contact will concern your action as a Personal Consultee for the resident. Further information on this will be given.

Protocol if a resident becomes upset by the process

Please be assured that should your relative appear to object or become uncomfortable or distressed the assessment will stop. We will take advice from the care home as to the best time to conduct an assessment with each resident. If it becomes necessary to stop the assessment it will be conducted at another time (communication with you will be made). Should the resident again appear uncomfortable the assessment will not continue and you will be contacted to act as Personal Consultee.

Confidentiality

It will not be possible to identify individuals in the research report or in subsequent publications. All data mapped from the care records and interviews are confidential. The research team will be the only individuals who are aware of your and your relative's name and data. The care home administrator has addressed this letter and will do for any future letters so the researchers do not hold your details. However if in the future the researchers do have your details (e.g. your telephone number for a follow-up call) then this will be kept separately from the data taken from the care records and in the interviews (if participated in). All such information will be destroyed after 7 years. The only time information may be disclosed to third parties is when the project researcher

perceives that your relative, yourself, or someone else is at risk of harm. The project researcher will discuss this issue with you before telling anyone else.

What to do next

Please see the enclosed Pre Data Collection Form, complete and return in the stamped and addressed envelope provided. The Form contains information on the following:

- a) We would like to invite you to an information meeting about the project to clarify any questions or concerns you may have. The researcher, Suzanne Hardy, and [CARE HOME MANAGER] will be present at [CARE HOME] at [DATE AND TIME]. You can speak to her there, however you can contact the project researcher at any time if you so wish via telephone or email. Attendance at the meeting is not mandatory. Please return the enclosed Pre Data Collection Form, email or telephone if you will attend the meeting, or if you would prefer to arrange a private meeting at a more suitable time.
- b) The intended date for the capacity-to-consent assessment with your relative is [DATE AND TIME]. You may be present at this assessment. If you do wish to be present and the time or date is inconvenient please notify the researcher on the enclosed Pre Data Collection Form and indicate when is suitable (or telephone).
- c) If you would prefer for your relative not to be assessed for their capacity-to-consent in the research project (their capacity to give permission for their care record to be viewed and for their care circumstances, particularly relating to ATs, to be the subject of interviews with their family and keyworker) please complete the relevant section on the enclosed Pre Data Collection Form (or telephone). You may still attend the information meeting for clarification on the project.

If you do not advise against an assessment but also do not wish to attend the information meeting or be present at the capacity-to-consent assessment, you do not need to complete and return the Form.

Thank you for taking the time to read this letter.

Yours sincerely,

Suzanne Hardy
Chief Investigator
PhD Candidate

Dr Karen Glaser
Reader in Gerontology
PhD Supervisor

Professor Anthea Tinker
Professor of Social Gerontology
PhD Supervisor

PRE DATA COLLECTION FORM



Room K4U.13
Institute of Gerontology
Department of Social Science, Health
and Medicine
King's College London
King's Building
The Strand
London
WC2R 2LS

[EMAIL ADDRESS]
[OFFICE TELEPHONE NUMBER]
[MOBILE NUMBER]

The role of Assistive Technology for Activities of Daily Living in enabling families to care for relatives with dementia in their location of choice

Study reference number: 12-IEC08-0025

Please indicate Yes or No to the items below.

	YES	NO
1. I will be attending the relatives meeting at [CARE HOME] on [DATE AND TIME] and will speak to Suzanne there.		

	YES	NO
2. I cannot attend the information meeting but would like to arrange a face-to-face information meeting with the Chief Investigator (Suzanne Hardy) at the care home. An appropriate date and time for me is _____ and my telephone number is _____. The project researcher will be in touch to confirm a meeting time. Contact via telephone or email if you prefer is equally possible.		

	YES	NO
3. I would like to attend the capacity-to-consent assessment with my relative on [DATE AND TIME] (if you have a preferred specific time please indicate here) _____		

	YES	NO
4. I would like to attend the capacity-to-consent assessment but a more suitable date and time is _____, my telephone number is _____. (The Chief Investigator will be in touch to confirm this time).		

OR	YES	NO
5. I would prefer for my relative not to be assessed for their capacity-to-consent. My relative's name is _____.		

If you do not advise against an assessment but also do not wish to attend the information meeting or be present at the capacity-to-consent assessment, you do not need to complete and return the Form in the self-addressed envelope provided.

Print name: _____

Signature: _____

Telephone number: _____

Your relation to the resident: _____

Resident Information Sheet

Institute of Gerontology
King's College London
King's Building
The Strand
London
WC2R 2LS
[EMAIL ADDRESS]
[MOBILE NUMBER]

Resident Information Sheet

A study looking at Assistive Technology for Activities of Daily Living

Hi, I'm Suzie Hardy



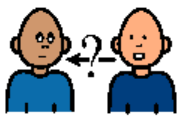
I would like to ask you to take part in a study

I am interested in the technology and devices your carers use to help care for you.





I would like to look at your care record here at the home to understand who helped you in the past and who helps you now.



I may ask some family and friends, and carers here at the care home to be interviewed about your care.

You can say

YES

or

NO



You can leave the study at any time



Please ask me any questions.

Assessment of Capacity Form and Supported Decision-Making Form

Assessing capacity-to-consent to participation in 'The role of Assistive Technology for Activities of Daily Living in enabling families to care for relatives with dementia in their location of choice'

Ethics Reference Number: 12-IEC08-0025

Name of person for whom assessment of capacity is being made:

Date of assessment:

Assessor:

Specify decision in question: Consent to take part in the project – permission to view their care record and be the subject of family, friends, neighbours and keyworker interviews if chosen for Stage Two

Assessment questions	YES (on balance of probabilities)	NO
1) Is there an impairment or disturbance in the functioning of mind or brain? (permanent or temporary)	<p>YES impairment is present <i>record symptoms/ behaviours, any relevant diagnosis</i></p> <p>If yes- continue questions a)–d)</p>	<p>NO impairment is not present, <i>record evidence (They will not lack capacity under the Act)</i></p> <p>If no – the person has capacity. Assessment is complete.</p>

2a) Despite all help given, is the person <u>unable</u> to understand the information relevant to the decision? Potential questions: What is your understanding of the decision in question? Do you think you understand what the research is about? Can you tell me why you think the decision needs to be made? Do you understand what will happen if you agree/don't agree to take part?	YES- unable to understand information. <i>Record steps taken to explain information and views/evidence why they did not understand it.</i>	No- able to understand information. <i>Record views/evidence to show they understood it.</i>
2b) Is the person <u>unable</u> to retain the information long enough to make the decision? Potential questions: Can you tell me what you understand about the research? Can you tell me what you think will happen if you agree/don't agree to take part?	YES- unable to retain information, <i>record any help given and evidence</i>	NO- able to retain information, <i>record evidence</i>
2c) Is the person <u>unable</u> to weigh the information as part of the decision	YES- unable to weigh information, <i>record evidence</i>	NO-able to weigh information, <i>record</i>

making process? What do you think will happen if you do/do not make this decision take part? What do you think will be good about taking part? Do you think there might be anything bad about taking part? Do you understand that you can say yes or no to taking part? Would you like to take part in the research?		<i>evidence</i>
2d) Is the person <u>unable</u> to communicate the decision? Has the person indicated consent/refusal by using verbal or non-verbal (e.g. sounds) means of communication?	YES- unable to communicate, <i>record evidence</i>	NO- able to communicate, <i>record evidence</i>

Conclusion:

If the answer is YES to Q1 and YES to any of the other questions then the person lacks capacity.

Outcome:

Supported decision making form for project 'The role of Assistive Technology for Activities of Daily Living in enabling families to care for relatives with dementia in their location of choice'

Ethics References Number: 12-IEC08-0025

Question	Yes/No Suggested action	Describe action agreed and undertaken
Does the person have all the relevant information needed to make the decision? If there is a choice, has information been given on the alternatives?		
Could the information be explained or presented in a way that is easier for the person to understand? Help should be given to communicate information wherever necessary. For example, a person with a learning disability might find it easier to communicate using pictures, photographs, videos, tapes or sign language.		
Are there particular times of the day when a person's understanding is better or is there a particular place where they feel more at ease and able to make a decision? For example, if a person becomes drowsy soon after they have taken their medication this would not be a good time for them to make a decision.		
Can anyone else help or support the person to understand information or make a choice? For example, a relative, friend or advocate.		

Resident Consent Form

RESIDENT CONSENT FORM



Institute of Gerontology
King's College London
King's Building
The Strand
London
WC2R 2LS
[EMAIL ADDRESS]
[MOBILE NUMBER]

The role of Assistive Technology for Activities of Daily Living

	YES	NO
I consent to my care record being viewed by the researcher to take information from it.		
	YES	NO
I have read and understood the resident information sheet and been given a copy.		
	YES	NO
I was given the opportunity to ask questions and I understand I can ask more if I need to.		
	YES	NO
I consent that my information can be stored at the Institute of Gerontology until the research is completed.		

	YES	NO
I understand that if I decide that I no longer wish to participate in this project, I can withdraw from it immediately without needing to give a reason.		

	YES	NO
I consent the anonymous data obtained from the information gathered will be used for analysis and research.		

	YES	NO
I would like to be sent information on the outcome of the study.		

	YES	NO
I consent to be contacted about future dementia research.		

Participant's Statement:

I _____ agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read/been read to both the notes written above and the information about the project, and understand what the research study involves.

Signed

Date

Researcher's Statement:

I _____ assessed the participant's capacity-to-consent to participate in the study and found them able to provide consent, explained the study and answered any questions from the participant honestly and fully.

Signed

Date

Courtesy letter for families whose relative gave their own consent



Institute of Gerontology
King's College London
King's Building
The Strand
London
WC2R 2LS
[EMAIL ADDRESS]
[MOBILE NUMBER]

[DATE]

Dear Sir/Madam

We are researchers at King's College London collaborating with [ANONYMISED CARE HOME ORGANISATION] in order to find out how the use of Assistive Technologies (ATs) for personal-care activities (that is, activities such as washing, dressing and eating) may play a role in enabling those families caring for a relative with a clinical diagnosis of dementia to care for them in their location of choice. The Social Care Research Ethics Committee has granted ethical approval for this project.

We contacted you earlier in the year to let you know about the project, explain its aims and invited you to an information meeting about the project. We notified you of the potential forthcoming capacity-to-consent assessment with your relative, and provided you with the option to attend the assessment if you so wished.

In accordance with the Mental Capacity Act 2005 we conducted a capacity-to-consent assessment with your relative to determine if they can make a decision on whether or not they would like to be in the project. Their participation concerns only permission for their care record to be viewed, and for their care circumstances and use of ATs to be the subject of interviews with family, friends and their keyworker, no other action will be required of them.

It was assessed that your relative possesses capacity-to-consent to the research. They made a decision that they would participate in the project (permission to view their care record) and signed a consent form. This is a courtesy letter notifying you of this event.

If you have any enquiries please do not hesitate to contact us using the details above. Many thanks for taking the time to read this letter.

Yours sincerely,

Suzanne Hardy
Chief Investigator
PhD Researcher

Dr Karen Glaser
Reader in Gerontology
PhD Supervisor

Professor Anthea Tinker
Professor of Social Gerontology
PhD Supervisor

Personal Consultee Letter and Personal Consultee Form



Room K4U.13
Institute of Gerontology
Department of Social Science, Health
and Medicine
King's College London
King's Building
The Strand
London
WC2R 2LS

[EMAIL ADDRESS]
[OFFICE NUMBER]
[MOBILE NUMBER]

[DATE]

Dear

We are researchers at King's College London collaborating with [ANONYMISED CARE HOME ORGANISATION] in order to find out how the use of Assistive Technology (ATs) for personal-care activities (that is, activities such as washing, dressing and eating) may play a role in enabling those families caring for a relative with a clinical diagnosis of dementia to care for them in their location of choice. The Social Care Research Ethics Committee has granted this project ethical approval.

We contacted you earlier in the year to let you know about the project and explain its aims and invited you to an information meeting about the project. We notified you of the potential forthcoming capacity-to-consent assessment with your relative and provided you with the option to attend the assessment if you so wished.

In accordance with the Mental Capacity Act 2005 we conducted a capacity-to-consent assessment with your relative to determine if they can make a decision on whether or not they would like to be in the project. Their participation concerns only permission for their care record to be viewed and for their care circumstances and use of ATs to be the subject of interviews with family, friends and keyworker, no other action will be required of them. Had it been assessed that they possessed capacity-to-consent, they would have made a decision on their participation in the project (permission to view their care record) and signed a consent form.

It was assessed that your relative does not possess capacity-to-consent on this decision (NB the capacity-to-consent assessment refers only and specifically to the decision of participation in the research, it does not relate to their capacity to make any other decision). As such, you have been identified as a person interested in the welfare of your relative. We are contacting you to be your relative's Personal Consultee in relation to this project.

Your involvement

We are asking you for advice as to whether in your opinion your relative would wish to take part in the project (have their care records viewed and their care circumstance to be the subject of interviews with family and professional carers) if they had capacity to make this decision. Please note that even if in your opinion your relative would participate in the project, their care record will not be viewed if:

- 1) They appear to object.
- 2) If viewing the record would be contrary to an advanced decision or any other statement by them which has effect.

We would like you to return the accompanying Personal Consultee Form in the enclosed stamped self-addressed envelope provided to indicate your opinion on this matter. If a reply is not received within three weeks we will be in further contact.

If you have any enquiries please do not hesitate to contact us using the details above. Many thanks for taking the time to read this letter.

Yours sincerely,

Suzanne Hardy
Chief Investigator
PhD Candidate

Dr Karen Glaser
Reader in Gerontology
PhD Supervisor

Professor Anthea Tinker
Professor of Social Gerontology
PhD Supervisor

PERSONAL CONSULTEE FORM



Institute of Gerontology
King's College London
King's Building
The Strand
London
WC2R 2LS
[EMAIL ADDRESS]
[MOBILE NUMBER]

The role of Assistive Technology for Activities of Daily Living in enabling families to care for relatives with dementia in their location of choice

Study reference number: 12-IEC08-0025

Please indicate Yes or No to every item on the table below. Note that items 3 and 4 are opposing statements.

	YES	NO
1. I understand that my relative has been assessed for the capacity-to-consent to their participation or non-participation in the project and has been found not to possess capacity. Therefore I have been contacted to advise on the matter.		

	YES	NO
2. I understand that for this project, my relative's participation only concerns their care record being viewed and mapped by the Chief Investigator, no other action is required of them.		

	YES	NO
3. I advise that in my opinion, the wishes and feelings of my relative would be likely to lead them to <u>agree to take part</u> in the project, if they had capacity in relation to the matter.		

	YES	NO
4. I advise that in my opinion, the wishes and feelings of my relative would be likely to lead them to <u>decline to take part</u> in the project, if they had capacity in relation to the matter.		

Print name: _____

Signature: _____

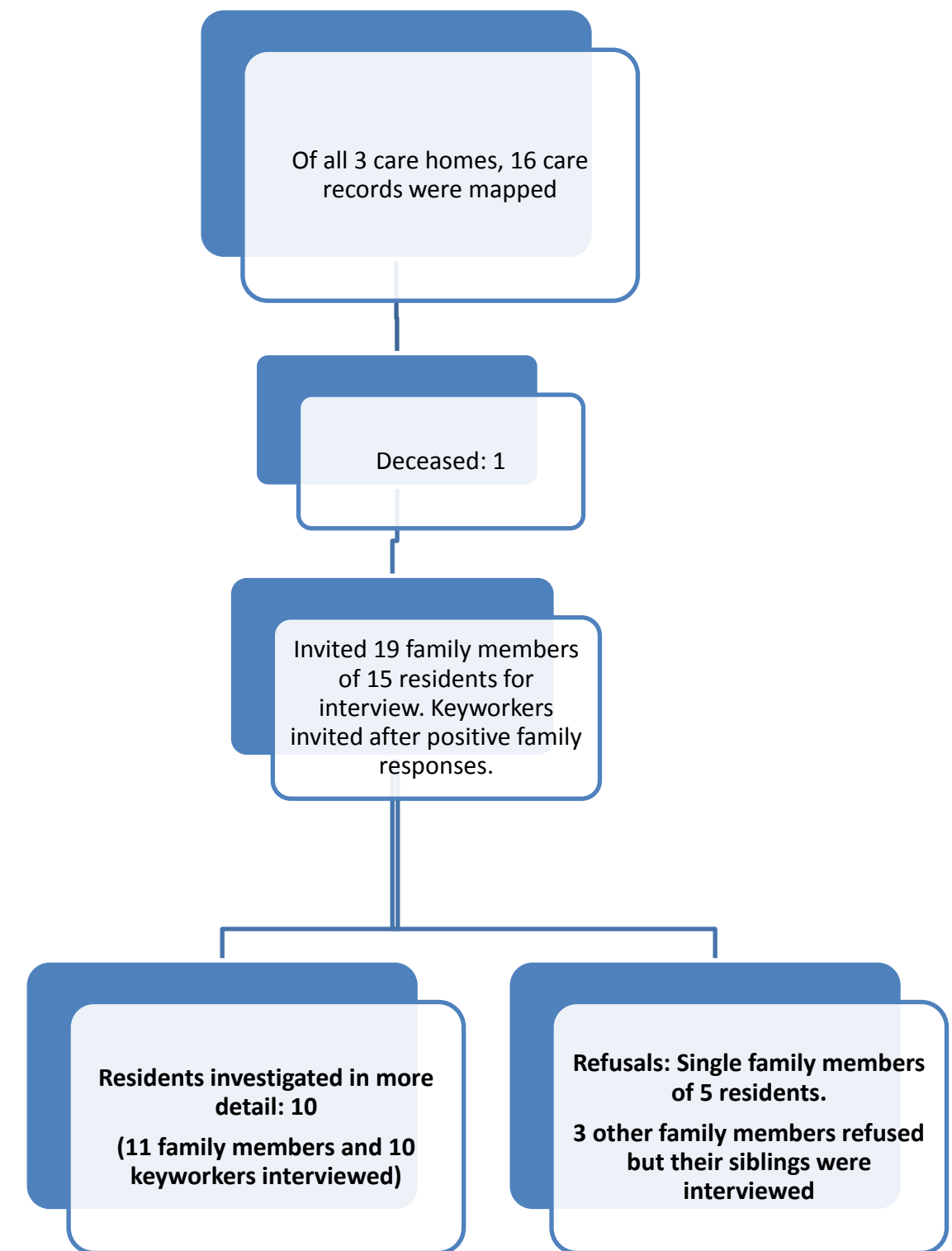
Relative's name: _____

Relation to resident: _____

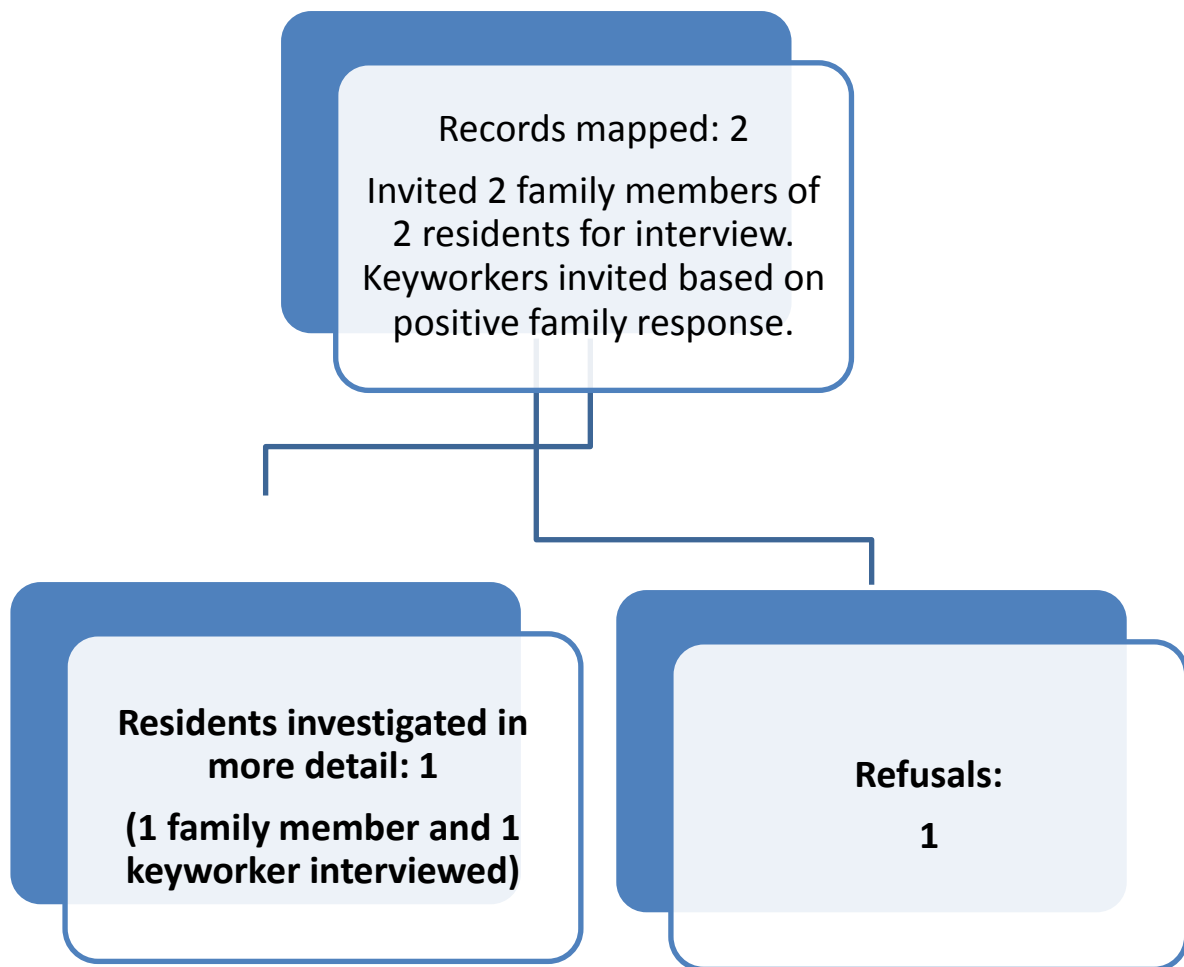
Please return this form in the self-addressed envelope provided.

Flowcharts of Stage Two participant numbers

Final numbers



Care home #1



Care home #2

Records mapped: 6

Invited 5 family members of 5 residents
for interview, as 1 resident died.
Keyworkers invited based on positive
family response.

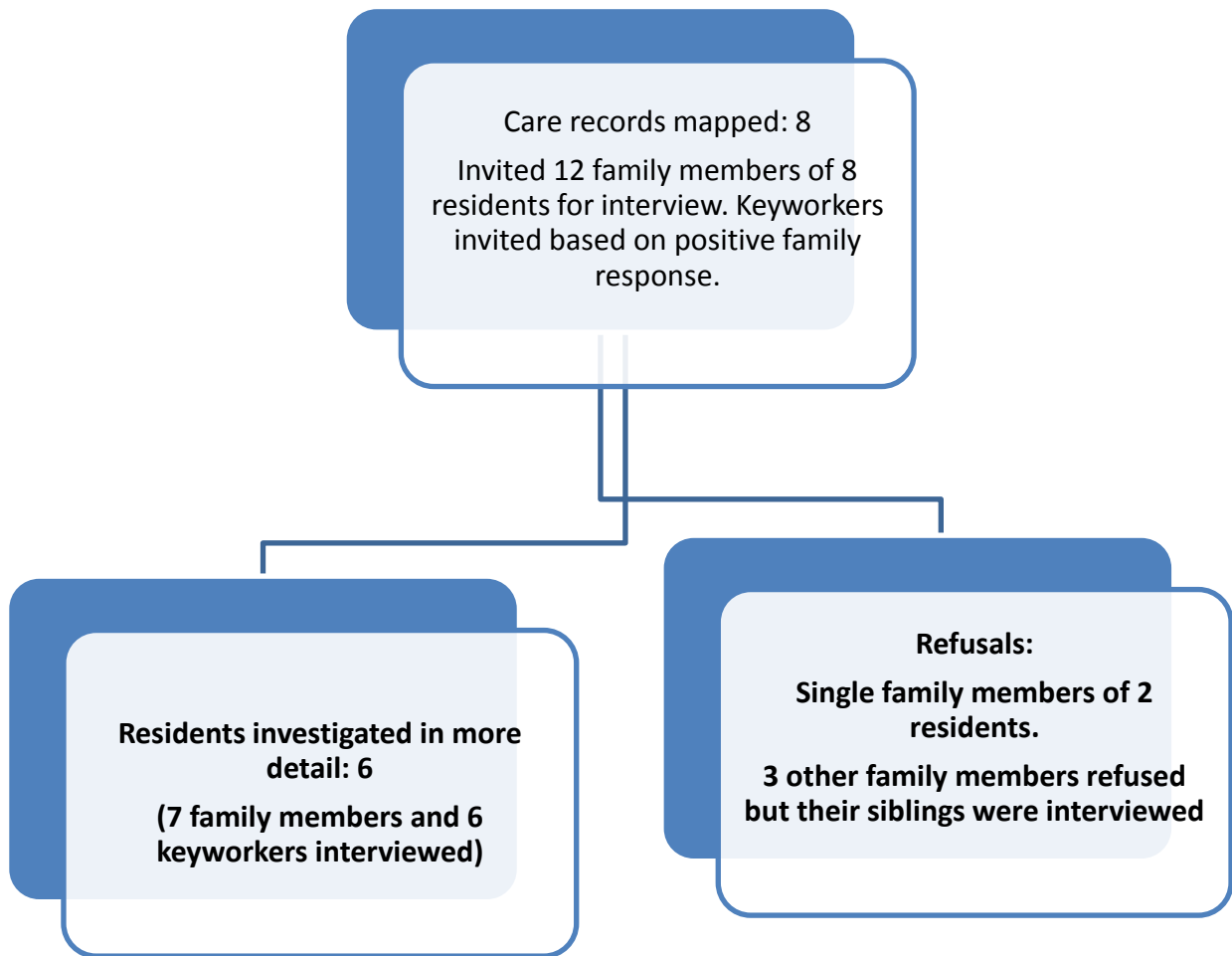
**Residents investigated in
more detail: 3**

**(3 family members and 3
keyworkers interviewed)**

Refusals:

2

Care home #3



Family and friends' interview topics

Pre-interview

Participant to re-receive the information sheet and asked to read it through. Participant to be given a brief introduction to the research that includes a description of ADLs (feeding, bathing, dressing, etc.) and the types of ATs for these activities that are the focus of the research. Participant to be told what will happen during the interview process and reminded that the interview will be recorded. Participant to be told that a transcript will be made from the digital recording. Participant to be told the method of analysis, reminded that they will remain anonymous, and that their data will be confidential. Participant given time to ask questions and sign two copies of the consent form, one of which is to be retained by the researcher.

Background

1. Can you tell me a little bit about [relative] and your relationship with them? *Prompt: length and frequency of contact with them (may be a distant aunt etc.).*
2. What first made you and others aware of your relative's dementia or cognitive problems? Were there any behaviours of particular concern? *Prompt: loss or lapses of recent memory, mood changes or uncharacteristic behaviour, poor concentration, problems communicating, getting lost in familiar places, making mistakes in a previously learned skill (e.g. cookery), problems telling the time or using money, changes in sleep patterns and appetite, personality changes, visuo-spatial perception issues.*
3. When was a diagnosis of dementia made? *Prompt: it may be since they moved to the care home.*

Difficulties with tasks and resulting care for the relative before the relocation

4. What difficulties with conducting personal-care tasks such as bathing, dressing or eating, did your relative experience before entering the care home? *Prompt: did you or your relative experience any areas of particular difficulty because personal-care was not being provided?*
5. What sort of informal care did your relative receive before entering the care home? What aspects were particularly challenging? *Prompt: was this before or after the diagnosis? i.e. care from respondent, neighbours popping in*
6. Did you perform any kind of personal-care tasks for your relative? *Prompt: if so, what kind of care tasks did you perform? Again, what was challenging?*
7. What aspects of their care were particularly rewarding for them and for you?
8. Can you tell me about any formal health or social services your relative received before he/she went into the care home? What aspects were particularly challenging or rewarding? *Prompt: was this before or after the diagnosis?*

Assistive Technology use before relocation

As you know we are particularly concerned with your experiences of personal-care for your relative, and the use of ATs for personal-care, at the time your relative was admitted to [care home]. By ATs we mean devices that may be used to assist with personal-care such as dressing, feeding and bathing. *Give examples.*

9. Can you tell me whether any ATs were used for your relative's care, and particularly if any of these were for bathing, dressing or feeding tasks, before your relative's entry into the care home?

If ATs were used:

10. Can you tell me why these particular types of ATs were chosen and used? *Prompt: who chose them?*
11. Can you tell me more about your experiences with these ATs? *Prompt: particularly those for personal-care tasks.*
12. What was particularly helpful or unhelpful about the use of each Assistive Technology? *Prompt: positive and negative perceptions, preferences and barriers.*
13. How do you think your relative felt about the use of these ATs for personal-care? *Prompt: freeing up some caring time, maintain sense of autonomy?*
14. How did you source information on ATs? What information did you find? *Prompt: were there any difficulties in sourcing information?*
15. How did you obtain the ATs that were used? *Prompt: were there difficulties obtaining ATs?*
16. Was health or social services involved in the use of these ATs? If so, how were they involved? *Prompt: did they assess the care situation, provide free temporary or permanent ATs, etc.?*

If ATs were not used:

17. Do you think using any type of ATs for any purpose would have helped you in caring for your relative? What do you think would have been useful and why?
18. Do you think there would have been anything unhelpful about the use of ATs?
19. What do you think prevented you or your relative from using ATs?
20. If you had wanted to use ATs, how would you have got information on them?
21. Where do you think you would have obtained ATs from? *Prompt: different routes e.g. through formal or community services, information on ATs from dementia groups, adverts, catalogues, etc. Were there any ATs they could not obtain?*

The decision for relocation of care

22. Can you tell me about the decision that was made to relocate your relative to [care home] - who was involved in the decision, when was it made and why? Was this your preferred choice? If not, what prevented you from having your preferred option? *Prompt: find out if resident was involved.*
23. Did difficulties with personal-care tasks contribute to the decision to relocate your relative? If so, how? *Prompt: if so, did the use of ATs delay the relocation decision? If not, were any behaviours a contributing factor?*
24. Please could you tell me a little bit about your experiences of locating a care home that met [relative]'s particular needs? *Prompt: the involvement of formal services in this, etc.*

In the care home

25. Can you tell me a little bit about your relative's care in the care home? Particularly has your relative begun to experience/ continued to experience difficulties with personal-care tasks such as washing and bathing, dressing and feeding?
26. Do you know which ATs are currently used for your relative's care in [care home]?
27. If they have difficulties with personal-care tasks: Do you know which types of AT for personal-care are currently used?
28. How do you feel about AT use at the care home? How do you think your relative feels about their use? Do you use any ATs with them?

Are there any other relevant issues on ADLs, ATs or relocation of care we have not discussed?

Keyworkers' interview topics

Pre-interview

Participant to re-receive the information sheet and asked to read it through. Participant to be given a brief introduction to the research that includes a description of ADLs (feeding, bathing, dressing, etc.) and the types of ATs for these activities that are the focus of the research. Participant to be told what will happen during the interview process and reminded that the interview will be recorded. Participant to be told that a transcript will be made from the digital recording. Participant to be told the method of analysis, reminded that they will remain anonymous and data will be confidential. Participant given time to ask questions and sign two copies of the consent form, one of which to be retained by the researcher.

Keyworker's background

1. Please could you describe the care and dementia care training and relevant qualifications you have to me?
2. How long have you worked at [care home]?
3. How long have you known [resident]?

The resident and their difficulties with tasks

4. Can you tell me a little bit about [resident]?
5. Can you tell me about [resident's] care? What aspects of their care are particularly challenging? What aspects of their care are particularly rewarding?
6. What difficulties does [resident] have with daily tasks and particularly those regarding personal-care, such as bathing, dressing or eating? *Prompt: can you tell me a little bit about these difficulties?*

Assistive Technology use

7. What kinds of ATs for personal-care tasks are used with [resident]? Why are these particular ATs used? What benefits and disadvantages are there of the ATs that are used?
8. Could you please tell me what kinds of ATs for other types of tasks are used for [resident]? Why are these particular ATs used?
9. How are decisions about AT use for ADLs made and who makes these decisions?
10. Do you know what [resident] thinks about AT use?

No use of ATs

11. Do you think using any type of ATs would help you in caring for the resident? If so, what do you think will be useful and why?

Relationship with the resident's family and friends

12. Can you tell me if [resident's] family and friends have involvement in their care? Are they involved in personal-care tasks?

If relatives are involved in care:

13. Do [resident's] family and friends use any of the ATs that are available to assist in their care?
14. Does the resident's family and friends have their own personal ATs that they use for assisting the resident when visiting? (if known)

Perceptions of AT use

15. Do you think AT use in the care home can facilitate or hinder relationships between the care home staff and the resident's family and friends? If so, how?

Are there any other relevant issues on personal-care ADLs or AT we have not discussed?

Interview Invitation Pack for family and friends: Invitation Letter, Study Form and Information
Sheet



Room K4U.13
Institute of Gerontology
Department of Social Science, Health
and Medicine
King's College London
King's Building
The Strand
London
WC2R 2LS

[EMAIL ADDRESS]
[OFFICE NUMBER]
[MOBILE NUMBER]

[DATE]

Dear

We are researchers at King's College London collaborating with [ANONYMISED CARE HOME ORGANISATION] in order to find out how the use of Assistive Technologies (ATs) for personal-care activities (that is, activities such as washing, dressing and eating) may play a role in enabling those families caring for a relative with a clinical diagnosis of dementia to care for them in their location of choice. This research is important because even though studies have shown that AT plays an important role in personal-care, and may act to delay admission to more intensive services, little research has investigated this issue among those with a cognitive impairment. We are therefore inviting family members and friends who have a relative with a clinical diagnosis of dementia currently residing in an [ANONYMISED CARE HOME ORGANISATION] care home to take part in this study. You have been chosen to be invited to participate in this study, although you are under no obligation to take part.

Background to the study

This study came about because although we know that AT plays an important role in personal-care, we know little about whether it acts to delay admission to more intensive services especially among those with cognitive impairments such as dementia. Difficulties with personal-care are important as we know that those with dementia experience significant declines in physical functioning. We therefore wish to find out more about the difficulties faced by those caring for a relative or friend with dementia and how these are related to entry into a care home. We also wish to understand what types of ATs, if any, are used for personal-care among those caring for an older relative prior to admission to a care home, and carer's preferences with respect to the use of ATs for personal-care. Finally, on care home admission we wish to understand how ATs for personal-care can best be used to improve both late-life care and social and family connections.

What does the project involve?

In collaboration with [ANONYMISED CARE HOME ORGANISATION], 'care maps' were created in the initial stage of this study for each person with a clinical diagnosis of dementia residing in an [ANONYMISED CARE HOME ORGANISATION] care home. These 'care maps' identified your relative's keyworker at the care home, their main informal carer and any other relevant family members and friends. The second stage involves interviews with those identified such as yourself about perceptions of your family member or friend's difficulties with personal-care, the role of AT (if any)

in assisting with personal-care, and how these difficulties with personal-care related to care home entry. Should you wish to participate, your relatives' [ANONYMISED CARE HOME ORGANISATION] keyworker will also be interviewed about your relative's care circumstances and AT use in order to understand their perceptions of how AT for can best improve late-life care on admission to a care home as well as social and family connections.

How can I find out more?

Please find enclosed the Information Sheet which explains more about the study. If you have any enquiries please do not hesitate to contact us via the above details.

How do I get involved or decline to participate?

Please complete and return the enclosed Study Form in the stamped self-addressed envelope within three weeks indicating if you would or would not like to participate. If we have not heard from you by this time, a researcher will telephone you to discuss the project. If you would like to take part they will arrange a time and date at your convenience for the interview.

Many thanks for taking the time to read this letter.

Yours sincerely,

Suzanne Hardy
Chief Investigator
PhD Candidate

Dr Karen Glaser
Reader in Gerontology
PhD Supervisor

Professor Anthea Tinker
Professor of Social Gerontology
PhD Supervisor



Room K4U.13
Institute of Gerontology
Department of Social Science, Health
and Medicine
King's College London
King's Building
The Strand
London
WC2R 2LS

[EMAIL ADDRESS]
[OFFICE NUMBER]
[MOBILE NUMBER]

Study reference number: 12-IEC08-0025

Family and Friends' Study Form

I have read the information provided and would be happy for a researcher to contact me to discuss the study and with regards to arranging an interview

☐

I would most prefer to be contacted via post/ email/ telephone (Please indicate as appropriate)

I have read the information provided and do not wish to participate in an interview

☐

Print name: _____

Signature: _____

Please provide details so that we can identify who you are for our records.

Address:

Telephone: _____

Email: _____

Please return this form in the stamped self-addressed envelope provided.



Room K4U.13
Institute of Gerontology
Department of Social Science, Health
and Medicine
King's College London
King's Building
The Strand
London
WC2R 2LS

[EMAIL ADDRESS]
[OFFICE NUMBER]
[MOBILE NUMBER]

Family and Friends' Information Sheet

The role of Assistive Technology for Activities of Daily Living in enabling families to care for relatives with dementia in their location of choice.

**Please read the following information before you decide
whether to participate in this research**

You are invited to take part in this research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information. **Your participation is completely voluntary.**

What is the purpose of the study?

The aim of this study is to understand carers' experiences of the difficulties that people with dementia may face in carrying out personal-care tasks and how these may be related to the need for entry into a care home. We also wish to understand carers' and keyworkers' perceptions of the role of Assistive Technologies (ATs) (if any) in assisting with personal-care activities among those with dementia.

In collaboration with [ANONYMISED CARE HOME ORGANISATION] 'care maps' were created in the first stage of the study for all residents with a clinical diagnosis of dementia in an [ANONYMISED CARE HOME ORGANISATION] care home. These 'care maps' identified the people around each person with dementia who are involved in their formal or informal care.

In the second stage of the study, we would like to interview the people identified, such as yourself, about your perceptions of your family member or friend's difficulties with , the role of AT (if any) in assisting with , and how these difficulties were related to entry into a care home. [ANONYMISED CARE HOME ORGANISATION] keyworkers will also be interviewed about your relative's care circumstances and AT use in order to understand their perceptions concerning how AT for personal-care can best be used to improve late life-care and social and family connections.

What will I have to do if I take part?

At a time convenient for you the researcher will arrange to interview you. This interview can take place anywhere convenient for you. A quiet room in the care home will be designated to the

researcher for interviews, or if preferred it can occur at your home or place of work. The interview can occur during the day, evening or at weekends.

To begin, you will again have the opportunity to read this Information Sheet, sign a Consent Form and have the opportunity to ask questions. The interview will concern your perceptions and experiences of the difficulties in assisting with your relative's personal-care needs and how these may have been related to the need for entry into a care home. We will also ask about the use of AT in relation to personal-care. The interview will have some set questions but will be more of an informative conversation, as you talk about your own experiences. The interview will last for approximately one hour and be recorded, subject to your permission, so that verbatim transcripts can be created from the recording.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw any data you have provided at any time up until the interview is transcribed and without giving a reason. A decision not to participate in the study will not impact upon your relationship with the care home in any way.

What are the possible benefits of taking part?

There are no immediate benefits to taking part. However participating in research projects is often a rewarding and interesting experience. The information we get from the study will help to better understand the use of AT in people's homes and the role AT plays in enabling families to care for a relative with dementia in their location of choice.

What are the possible disadvantages of taking part?

There are no foreseeable risks in taking part in the study. The main disadvantage to taking part in the study is that you will be donating around an hour of your time

It is possible that you may find answering some of the questions distressing or upsetting. If this occurs you may wish to pause or stop the interview. You could then: terminate and withdraw your data (the interview recording would be deleted), terminate the interview and allow the interview recording until then to be used in the research, or carry on with the interview when you are ready.

Confidentiality

Everything you say in the interview is confidential unless you report something that indicates you or someone else is at risk of harm. The interviewer will discuss this issue with you before telling anyone else.

Your participation is voluntary. If you change your mind, you are free to stop your participation and to have your data withdrawn without giving any reason. All data for analysis will be anonymous.

What if something goes wrong?

We don't envisage any major risks associated with taking part in this study. If this study has harmed you in any way you can contact King's College London using the details at the bottom of this Sheet for further advice and information.

What will happen to the results of the study?

The findings will be used to contribute towards wider research in the areas of AT and dementia. The results of the study will be represented in scientific journals and a research thesis, and will be used to inform policy. A report of the study findings can be sent to you once the research has been completed.

Contact for further details:**Suzanne Hardy****Chief Investigator and PhD Candidate**

Institute of Gerontology
King's College London
King's Building
The Strand
London
WC2R 2LS
Email: [EMAIL ADDRESS]

Dr Karen Glaser**Reader of Gerontology and PhD Supervisor**

Institute of Gerontology
King's College London
King's Building
The Strand
London
WC2R 2LS
Email: [EMAIL ADDRESS]

Professor Anthea Tinker**Professor of Social Gerontology and PhD Supervisor**

Institute of Gerontology
King's College London
King's Building
The Strand
London
WC2R 2LS
Email: [EMAIL ADDRESS]

Interview Invitation Pack for keyworkers: Invitation Letter, Study Form and Information Sheet



Room K4U.13
Institute of Gerontology
Department of Social Science, Health
and Medicine
King's College London
King's Building
The Strand
London
WC2R 2LS

[DATE]

[EMAIL ADDRESS]

[OFFICE NUMBER]

[MOBILE NUMBER]

Dear

We are researchers at King's College London collaborating with [ANONYMISED CARE HOME ORGANISATION] in order to find out how the use of Assistive Technologies (ATs) for personal-care activities (that is, activities such as washing, dressing and eating) may play a role in enabling those families caring for a relative with a clinical diagnosis of dementia to care for them in their location of choice. This research is important because even though studies have shown that ATs play an important role in personal-care, and may act to delay admission to more intensive services, little research has investigated this issue among those with a cognitive impairment. We are therefore inviting the keyworkers of residents with a clinical diagnosis of dementia currently residing in an [ANONYMISED CARE HOME ORGANISATION] care home to take part in this study. You have chosen to be invited to participate in this study, although you are under no obligation to take part.

Background to the study

This study came about because although we know that ATs play an important role in personal-care, we know little about whether it delays admission to more intensive services especially among those with cognitive impairments such as dementia. Difficulties with personal-care are important as we know that those with dementia experience significant declines in physical functioning. We therefore wish to find out more about the difficulties faced by those caring for a relative or friend with dementia and how these are related to entry into a care home. We also wish to understand what types of ATs, if any, are used for among those caring for an older relative prior to admission to a care home, and carer's preferences with respect to the use of AT for personal-care. Finally, on care home admission we wish to understand how ATs for personal-care can best be used to improve both late-life care and social and family connections.

What does the project involve?

We have created a 'care map' for each resident with a clinical diagnosis of dementia that you are a keyworker for. The aim was to create a detailed picture of these residents' care and social networks, including their formal carer(s), main family carer, and other relevant family members and friends who have knowledge of their care before and after they came to live at the care home. This involved working through the residents' care record.

The second stage of the project involves selecting a number of residents to investigate in more detail. We will be conducting interviews with selected family members and friends about their

relative with dementia's difficulties with personal-care, the role of AT (if any) in assisting with personal-care, and how these difficulties associated with personal-care were related to care home entry. As an [ANONYMISED CARE HOME ORGANISATION] keyworker for a resident who has been selected, we are inviting you to an interview to understand how AT for personal-care can best improve late-life care and social and family connections at a the care home in relation to the person you are a keyworker for. This interview will be conducted during your working hours. If the family of the resident does not wish to be interviewed, you will not be interviewed about the resident.

How can I find out more?

Please find enclosed the Information Sheet which explains more about the study. If you have any enquiries please do not hesitate to contact us via the contact details.

How do I get involved or decline to participate?

If you would prefer not to be contacted by the research team regarding an interview please return the enclosed Study Form in the stamped self-addressed envelope within three weeks stating that you do not wish to be contacted. If we have not heard from you by this time, a researcher will telephone you at the care home to discuss the project. If you would like to take part they will arrange a time and date at your convenience to meet with you.

Many thanks for taking the time to read this letter.

Yours sincerely,

Suzanne Hardy
Chief Investigator
PhD Candidate

Dr Karen Glaser
Reader in Gerontology
PhD Supervisor

Professor Anthea Tinker
Professor of Social Gerontology
PhD Supervisor



Room K4U.13
Institute of Gerontology
Department of Social Science, Health
and Medicine
King's College London
King's Building
The Strand
London
WC2R 2LS

[EMAIL ADDRESS]
[OFFICE NUMBER]
[MOBILE NUMBER]

Study reference number: 12-IEC08-0025

Keyworker Study Form

I have read the information provided and do not wish to participate in an interview

☐

Print name: _____

Signature: _____

Care home: _____

Please return this form in the stamped self-addressed envelope provided.



Room K4U.13
Institute of Gerontology
Department of Social Science, Health
and Medicine
King's College London
King's Building
The Strand
London
WC2R 2LS

[EMAIL ADDRESS]
[OFFICE NUMBER]
[MOBILE NUMBER]

Keyworker Information Sheet

The role of Assistive Technology for Activities of Daily Living in enabling families to care for relatives with dementia in their location of choice.

Please read the following information before you decide whether to participate in this research

You are invited to take part in this research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information. **Your participation is completely voluntary.**

What is the purpose of the study?

The aim of this study is to understand carers' experiences of the difficulties that people with dementia may face in carrying out personal-care tasks and how these may be related to the need for their relative's entry into a care home. We also wish to understand keyworkers' and family carers' perceptions of the role of Assistive Technologies (ATs) (if any) in assisting with personal-care activities such as washing, dressing and feeding among those with dementia.

What will I have to do if I take part?

We have already created 'care maps' for each resident with a clinical diagnosis of dementia in [ANONYMISED CARE HOME ORGANISATION] care homes. These 'care maps' identified the people around each person with dementia who are involved in their formal or informal care. We would like to select a number of those thus identified for interview; that is, family members and friends as well as keyworkers. Interviews with keyworkers will investigate their perceptions of the different ATs used for personal-care tasks with the person with dementia whilst in the care home, their perceptions of AT's effectiveness in improving or maintaining the resident's sense of independence, and AT's usefulness in improving social relations with others residing in the care home and with the individual's family members and friends.

The interview will take place in a designated quiet room at the care home. To begin, you will again have the opportunity to read this Information Sheet, sign a Consent Form and ask questions. The interview will concern your perceptions of how ATs have been used with the person with dementia and its value, and whether ATs can improve care home and family relations. The interview

will have some set questions but will be more of an informative conversation, as you talk about your own perceptions and experiences. The interview will last for approximately one hour and be recorded so that verbatim transcripts can be created. You are free to withdraw any data you have provided at any time up until it is transcribed and without giving a reason.

Do I have to take part?

No, it is up to you whether you take part in either stage of the study. If you decide to take part you are still free to withdraw any data you have provided at any time up until the interview is transcribed and without giving a reason. A decision not to participate in the study will not impact upon your relationship with the care home in any way.

What are the possible benefits of taking part?

There are no immediate benefits to taking part. However participating in research projects is often a rewarding and interesting experience. The information we get from the study will help to better understand the use of ATs in people's homes and the role ATs play in caring for a person with dementia.

What are the possible disadvantages of taking part?

There are no foreseeable risks in taking part in the study. The main disadvantage to taking part in the study is that you will be donating around an hour of your time. However interviews will be arranged during work hours at a time most convenient for you and your workload, as agreed by the care home manager.

It is possible that you may find answering some of the questions distressing or upsetting. If this occurs you may wish to pause or stop the interview. You could then: terminate and withdraw your data (the interview recording would be deleted), terminate the interview and allow the interview recording until then to be used in the research, or carry on with the interview when you are ready.

Confidentiality

Everything you say in the interview is confidential unless you report something that indicates you or someone else is at risk of harm. The interviewer will discuss this issue with you before telling anyone else.

Your participation is voluntary. If you change your mind, you are free to stop your participation and to have your data withdrawn without giving any reason. All data for analysis will be anonymous.

What if something goes wrong?

We don't envisage any major risks associated with taking part in this study. If this study has harmed you in any way you can contact King's College London using the details at the bottom of this Information Sheet for further advice and information.

What will happen to the results of the study?

The results will be used to contribute towards wider research in the areas of AT and dementia. The results of the study will be represented in scientific journals and a research thesis, and will be used to inform policy. A report of the study findings can be sent to you once the research has been completed.

Contact for further details:

Suzanne Hardy

Chief Investigator and PhD Candidate

Institute of Gerontology

King's College London

King's Building

The Strand

London

WC2R 2LS

Email: **[EMAIL ADDRESS]**

Dr Karen Glaser

Reader of Gerontology and PhD Supervisor

Institute of Gerontology

King's College London

King's Building

The Strand

London

WC2R 2LS

Email: **[EMAIL ADDRESS]**

Professor Anthea Tinker

Professor of Social Gerontology and PhD Supervisor

Institute of Gerontology

King's College London

King's Building

The Strand

London

WC2R 2LS

Email: **[EMAIL ADDRESS]**

Interviewee Consent Form

INTERVIEWEE CONSENT FORM



Institute of Gerontology
King's College London
King's Building
The Strand
London
WC2R 2LS
[EMAIL ADDRESS]
[MOBILE NUMBER]

The role of Assistive Technology for Activities of Daily Living in enabling families to care for relatives with dementia in their location of choice

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

	YES	NO
I have read the information sheet and been given a copy. I was given the opportunity to ask questions.		

	YES	NO
I consent to my interview being recorded.		

	YES	NO
I consent that the information I provide about me and the care home resident with a clinical diagnosis of dementia can be stored at the Institute of Gerontology until the research is completed. Any future work or extension of the project will be subject to review by a research ethics committee.		

	YES	NO
I understand that if I decide that I no longer wish to participate in this project, I can notify the researchers involved and withdraw from it immediately without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to the point of transcription.		

	YES	NO
I consent the anonymous data obtained from the information gathered will be used for analysis and research.		

	YES	NO
I consent to be contacted about future dementia research.		

	YES	NO
I would like to be sent information on the outcome of the study.		

Participant's Statement:

I _____ agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed

Date

Researcher's Statement:

I _____ have explained the study and answered any questions from the participant honestly and fully.

Signed

Date

Appendix 5: Stage One vignettes

Case A Stage One vignette

Case A is a female in her early 80s. She has VaD, which was diagnosed seven years ago.

Pre-relocation

Case A was born in a different area of the country to where she now lives. Of multiple siblings, only Case A and one sister are still alive. She married her husband in the 1950s but was widowed in the 1970s. Her first daughter died at only a few months old due to a chronic illness. Her adult daughter, 'A1', has the same condition as her deceased sister, and up until the mid-2000s Case A would have to get up early every day to help A1; now she enjoys a lie-in. She also likes travelling and cruises, TV soaps and reading her newspaper. At home she was diagnosed with kidney disease, hypertension, spinal stenosis and depression.

Relocation, capacity and care home life

Case A relocated to the care home in February 2012. She is unaware of her dementia. Although she has been honestly told why she lives at the care home, she thinks she is there for a holiday while her daughter gets better. She also believes that she should go home every evening, in the belief that she works at the care home. She sometimes thinks that Care home #1 is a house where the staff live and that she is visiting them, having walked there that morning. She can be unsettled and express a wish to go home, collecting personal items before she 'leaves' to walk throughout the corridors.

The decision to relocate was made by her daughter as Case A is vulnerable and there were safeguarding concerns. Capacity assessments show that she is able to make some daily choices but lacks capacity to make decisions regarding her care and safety. Although she has insight, confusion distresses her. She can confuse reality with delusions. She constantly repeats questions and conversations. She has occasional difficulty communicating with others.

She is often visited by her daughter, and sometimes by her son-in-law and her friends. Her daughter also takes Case A out for lunch and to medical or social appointments.

Case A smokes up to two cigarettes per day. The care home staff take her outside for a cigarette, although she may sometimes use an e-cigarette indoors. She reads a daily paper. She has lots of memories when looking at old photos. She requires staff assistance to participate in social activities and to support and manage her mental well-being, sexuality, spirituality, anxiety and depression. Her anxiety is related to cigarettes and her wish to go to the shop to buy more. She is generally able to sleep well although the activities that form her night routine require some support. Her bed call-bell is kept within her reach at night.

Medical and sensory conditions

In addition to VaD her co-morbidities include: a stroke, arthritis, osteoporosis, cataracts, two hip replacements, hypercholesterolemia, a knee replacement, and proneness to UTIs. Her blood pressure has decreased from a first reading of 158/62mmHg (considered high) to a most recent reading of 140/73mmHg (considered pre-high). She has painful knees, shoulders and legs because of arthritis and has laser acupuncture and Movelat gel applied to alleviate this. She has no problems with her hearing. She wears spectacles and has annual eye tests. She sees a podiatrist, dentist and psychiatrist.

In May 2013 she had blood in her knickers but said it was a period that comes and goes. Staff found no blood coming from her vaginal or anal area. She was referred to the GP who referred her for a vaginal scan. No more information than this was in the care record at the time of mapping.

She is fully dependent on staff for administration of medications. She takes 30mg Atalopram daily for depression. She is sometimes reluctant to take her medication.

Mobility and orientation

Although not at risk of falls according to her STRATIFY score, Case A occasionally requires support from carers when transferring due to poor balance and pain in her knees. However her balance when sitting is good. Staff have recently noticed that she sometimes becomes breathless on exertion. She has a stick for walking but refuses to use it.

She has disorientation of time, person and place. She is sometimes unable to locate her bedroom or bathroom if tired.

Case A's bedroom contains a low divan bed to enable her to transfer into it more easily. She had a Bed-Rail Assessment in February 2013, but does not require them.

Washing, bathing and skin integrity

Although Case A can perform personal hygiene activities herself she sometimes requires verbal prompting with these. For example on one day in April 2013 she took herself to the shower room and independently had a shower and washed her hair. On another day in the same month she required prompting and supervision to shower. She may sometimes be confused about whether she had a shower or not when asked later in the day. She is known to prefer a daily shower but sometimes refuses it. Her Risk Assessment shows that Case A is able to use the walk-in shower room alone. She reads the step instructions on the bathroom wall to guide her when showering alone.

Frequent Waterlow Pressure Risk Assessments demonstrate that Case A has changed from being At Risk to at Very High Risk of having pressure sores. Therefore she is encouraged to keep mobile.

Grooming

Case A has her own teeth. She can perform oral-care activities but sometimes requires verbal prompting by staff or the toothpaste to be put onto her toothbrush and left for her to notice and use later. Carers must ensure her nails are clean. Case A requires help to dry her hair.

Dressing and body temperature

Although she requires minimal dressing assistance, Case A is usually helped to put on a bra by one carer because of a stiff shoulder. She can usually prepare herself for bed. She needs to be encouraged to change clothes as she can wear items for multiple days. She cannot perceive laundry as being dirty even if there are visible marks and so can be reluctant to change when it is suggested to her. As such carers have put a sign in her en-suite reminding her of what to do with dirty laundry. She sometimes puts on clothes incorrectly. She has few problems with managing her own body temperature but if leaving the care home she may need reminding to put on a coat.

Bathroom use and continence

Case A is usually able to locate her toilet. She has a raised, winged toilet seat in her bathroom. She is not incontinent, and requires one laxative drink per day for constipation. She does not like its taste so this has to be mixed into orange juice.

Eating

Her height is 152cm and her weight is 70.7kg, translating into a Body Mass Index of 30.6kg/m² (obese). She has low risk of malnutrition. She must drink plenty of fluids to prevent recurring UTIs.

She eats and takes fluids well, although at a slow pace. She can make herself a cup of tea and prepare snacks in the dementia ward kitchenette. She has had a Risk Assessment for the kettle. She is sometimes reminded to come to the dining room for meals. On one occasion in May 2013 she ate salad cream believing it to be yoghurt. She is not allowed alcohol because of her pain medication but has non-alcoholic beer some evenings.

End of life plan

A DNR Form was completed in September 2012. Case A has been assessed as unable to make her own arrangements regarding the end of her life. Her notes on palliative care show that the environment should be light and airy as she is frightened of the dark.

Case B Stage One vignette

Case B is a female in her mid-90s. She has VaD.

Pre-relocation

She married her husband in the 1940s but is now widowed. She has one daughter, B1, two grandsons and one great-grandson.

Relocation, capacity and care home life

She relocated to the care home in February 2009. Prior to her institutionalisation, the records show that Case B lived in the same address as her daughter, B1.

When she entered the care home she had the capacity to make some uncomplicated everyday decisions regarding her care. Now, her capacity level leaves her vulnerable.

When Case B first moved to the care home she was able to communicate with staff, although the notes advised them to speak clearly and at eye contact level otherwise she would not understand what they were saying. Now she has difficulty communicating with others. She reacts very badly to loud noises so has her favourite music on the radio, such as Mozart and Bach pieces, to soothe her. She used to express her fear of being mentally ill, and does not know about her dementia. She also frequently said she wanted to go home and wanted her parents to come and fetch her. Before she was bed-bound she required staff assistance to participate in social activities and to support and manage her mental well-being, behaviour, sexuality, spirituality, anxiety and depression. She often showed signs of anxiety such as calling out 'help', although she did not always know why she called 'help' just felt she needed 'help' at that time. Reassurances from staff helped this most of the time. She also intermittently appeared low in mood. Staff managed these behaviours with distraction techniques such as asking her to fold napkins and sort socks. Now she cannot do these activities. She also banged her head or bit her finger when agitated. Sometimes this was related to her increasing obsession with using the toilet and being anxious about continence accidents. As she could not get to the toilet without help she would scream or bang doors until she was attended to. There was a noticeable reduction in calling out by November 2012 due to illness. After that she was generally very calm.

Before she was bed-bound and uncommunicative, if she felt sleepy she would go to the sofa, pat it and ask to lie down on it for a while. She generally has a disturbed sleep pattern and can be confused on waking. She only sleeps for short periods of time.

Medical and sensory conditions

In addition to her VaD, Case B's co-morbidities include: osteoporosis, migraines, occasional UTIs, constipation and epistaxis (nosebleeds). She has poor eyesight. Although she has an annual eye test the optician is unable to check her properly because of her dementia. She has a hearing aid for deafness. She requires staff to administer all her medication.

Mobility and orientation

Although she was mobile when she relocated, Case B is now bed-bound. Prior to being bed-bound Case B had poor mobility and slight pain on movement. Sometimes she could walk with the help of two carers for short distances. She could self-propel in a wheelchair and had a Risk Assessment for a lap belt for this when she first arrived at the care home. In November 2012 she was assessed by the physiotherapist for a water-chair but one could not be found to fit her body. Case B is now bed-bound because of a contracted right leg.

When she was mobile, her poor short-term memory meant that she needed prompts and reminders to remain oriented. When she could speak she asked frequently where she was and the day and year. As soon as she left her bedroom she could not remember where she was and went into other resident's rooms looking for her room.

She had a bed-rail assessment in May 2010 because she was at risk of falling out of bed. The assessment noted that she feels secure with them on and holds on to them. There are also full-length bumpers for these. The bed-rails are removed during ADL care. She does not require a pressure alarm system because of her immobility.

Washing, bathing and skin integrity

Case B receives bed baths. She doesn't mind about the gender of carers when she is washed. Her Waterlow score demonstrates that she is at Very High Risk of pressure sores of the sacrum and other areas because of being bed-bound. As such she has cream applied to her skin and is repositioned every two hours with slide-sheets. The skin at the back of her knees requires special attention because of her contracted legs.

Grooming

There were minimal data in the care record regarding grooming activities. She used to enjoy putting on lipstick but no longer wears it.

Dressing and body temperature

Case B receives full support to dress, although is encouraged to choose her clothes if possible. In the past she was particular about her clothes and preferred beige and other neutral colours. She has to wear socks to stop her toenails scratching her in between podiatrist visits.

Bathroom use and continence

Case B is doubly incontinent. She used to display challenging behaviour such as screaming, self-harm and banging furniture when anxious about her need to go to the toilet and lack of staff attendance. Before she was bed-bound it was noted that she was only incontinent at night so staff used a yellow continence pad and put her on the commode twice during the night. She now uses continence protection pads exclusively for her elimination needs as her contracted leg means she cannot sit on a toilet or commode. She is also on Laxide (a laxative drink) to help her open her bowels.

Eating

Her weight when she moved to the care home was 57.5kg and has changed over time: 42.6kg in July 2012 then up to 47kg in November 2012, down to 41.6kg in February 2013 then up to 46kg in April 2013. The stand-aid hoist is used to lift her up and weigh her. Her BMI has ranged from 23.9kg/m² to a low of 19kg/m² (both still in normal weight range).

Case B is fed by staff during meals who are instructed not to rush her and to ensure her mouth is clear in between mouthfuls. Food is now liquidised and drinks are thickened as she has swallowing issues related to reflux for which she was treated in the past. A SALT assessment in May 2011 showed she had reduced oro-motor musculature and a slight tremor in her tongue. Her portions are smaller to help reduce clear phlegm that was coming up after food. Her reflux was also managed by suctioning around her mouth (not behind the throat).

End of life plan

A DNR Form was completed in January 2013. Case B has been assessed as unable to make her own arrangements regarding the end of her life.

Case C Stage One vignette

Case C is a male in his mid-80s. He has AD which was diagnosed 12 years ago.

Pre-relocation

Case C married his wife in the 1950s and had one son and one daughter. However his son died aged 18 years. His daughter has four children. He lived at home with his wife, 'C1', in a bungalow in the same town where Care home #2 is located. They moved to the bungalow in approximately 2006 when his AD progressed. At home he had six-monthly reviews by Older People's Mental Health to track the progression of his dementia. He was incontinent and had pads for these. One formal carer entered the house three times per day to assist with personal care, change his continence pad and assist with other toileting activity. They also put him to bed in the evening. C1 paid £60 for a private sitter once a week on Tuesdays. She also paid £10 to a charity for a few hours respite care on Thursdays. Case C had a total cholecystectomy (to remove his gall bladder) in 2000 and an inguinal hernia in 2001. He used a walking frame after a fall in September 2001. Case C has a PhD in Science and likes science documentaries, history, railways, travel and wildlife.

Relocation, capacity and care home life

Case C relocated to the care home in August 2012. The decision to relocate came after the County Council conducted a comprehensive health and social care individual needs assessment in August 2012. The outcome of this was a recommendation to a care home. This was because C1, who was the main carer, found providing assistance to Case C increasingly difficult due to his changing physical ability when transferring; he had problems with mobility even with the use of a frame and carer supervision. Case C expressed his wish to stay at home but agreed that he didn't want to put his wife in a position she was struggling with. He was also having problems retaining information.

C1 visits Case C regularly according to the daily log in the care record. She is very involved in his care.

In March 2013, Case C had a marked deterioration in function that occurred over a one-week period. From then, he now no longer responds to commands. He has fluctuating capacity which leaves him vulnerable. He cannot express his needs through verbal communication alone or understand requirements of others, but may use non-verbal communication. He will only speak when spoken to. Case C requires a high level of support to take part in activity programmes or fulfil his social needs. He used to take part in social activities such as quizzes, games poetry and reminiscence activities. He should not watch violent films but enjoys rugby. He appears settled both mentally and emotionally with no anxiety. He exhibits calm behaviour. Although he spends a lot of time in his room, he is not depressed. He does not require assistance to sleep. When asleep, his door is closed but he is checked hourly by night staff.

Medical and sensory conditions

Case C was on Galantamine Syrup for AD, 12mg in the morning and 12mg in the evening. This had been changed from a chew tablet after he began to have difficulties taking it. The notes do not clarify whether he still takes this syrup.

In addition to AD, he experienced a chest infection in November to December 2012. In April 2013, he was coughing and so sat up to aid his breathing; he spat out his cough medicine. In June 2012, he collapsed. This was attributed to temporal lobe atrophy consistent with a symptomatic postural drop (sudden drop in blood pressure) and AD. He has hearing weakness. Staff administer all medication.

Mobility and orientation

A STRATIFY assessment demonstrated that Case C is a High Falls Risk as he can forget that he cannot walk on his own. He can move his arms but his other mobility is restricted. He must have two carers who use a hoist and handling belt for all of his transferring activities, including sitting on the toilet. He sometimes uses a walking frame plus two carers to walk but commonly has a wheelchair. He can reposition himself when sitting a chair but may need prompting to push himself back. No stairs assessment is required because his bedroom is on the ground floor and he is unlikely to use the stairs. He has no pain at movement or at rest.

He has marked disorientation of time, person or place and fails to recognise and appropriately use everyday items. He cannot locate his bedroom.

Two carers must use a slide-sheet to reposition him while in bed. The height of his bed can be varied as appropriate for the carer. He has bed-rails but not bumpers on these as the care record notes that he doesn't try to get out of bed on his own. However it previously noted that he might. There is therefore inconsistency in the written record as to whether bed-rail bumpers are or are not needed. The bed-rail, mattress and bed surround are appropriately spaced to prevent risk of entrapment. Whether he has or does not have a pressure-relieving mattress is indeterminable from the care record. He does not have soft cushioning on the floor or a pressure alarm system.

Washing, bathing and skin integrity

Case C requires two care staff to assist with bathing, bed bathing or other washing activity. Staff shampoo his hair. He uses the bath hoist if having a traditional bath. Case C is washed by male and female staff and there are no concerns registered by his family about this.

Waterlow Pressure Risk Assessments have shown that Case C may be at risk of pressure sores, although he has had none so far. Care home staff cream his head, legs and arms to help with skin integrity and manage eczema.

Grooming

Case C receives shaves with an electric razor or sometimes has a wet shave. Care home staff conduct these activities on him.

Dressing and body temperature

Care home staff provide complete assistance to dress Case C, although try to involve him in choosing his clothes. He cannot regulate his body temperature so requires support for this.

Bathroom use and continence

Case C is doubly incontinent. He uses incontinence pad protection in the form of pull-ups. He is also hoisted over a pan or commode where he usually opens his bowels. Staff are told to change the pad regularly as leaving it wet tends to lead to sore skin on his genitals. He sometimes takes Movicol (a laxative), although not daily as he generally goes to the toilet well.

Eating

Case C is of medium build. His weight on admission was 78.2kg and slowly reduced; it was 74kg at the time of care mapping. His BMI at this time is 22kg/m² (normal weight).

He requires one carer to provide prompting and physical assistance for food and fluids. He cannot use cutlery successfully. He also used to forget how to swallow so held food in his mouth or kept chewing and eventually spat the food out. As meals took a long time, he would also lose interest in

the activity. As such, and by recommendation of a SALT assessment, his diet of normal consistency food was stopped in February 2013 and a soft diet plan began. He now also has thickening fluid put into his drinks as he began to find it difficult to swallow liquids. C1 chooses his menus each Monday for the week ahead.

End of life plan

Case C has a DNR Form and living will related to his advance directives. These include notes made in March 2013 to refuse all medical treatment especially that which aims to prolong or artificially sustain life. He consented only to medical treatment that aimed to help make him comfortable, and so far as possible, free from pain. He has been assessed as unable to make his own arrangements regarding the end of his life.

Case D Stage One vignette

Case D is a female in her late 90s. She has VaD.

Pre-relocation

Case D was born in a different area of the country to where she lives now. She has skills in dress designing and making. She was married in the 1940s but is now widowed. She has one daughter, D1, two granddaughters and a grandson. She enjoyed flower-arranging and owning dogs. At home she suffered with cardio-vascular disease and hypertension, macular degeneration and arthritis in her hands. She had two knee operations and a right hip replacement. She also had some injuries from falls including a left wrist fracture.

Relocation, capacity and care home life

Case D relocated to Care home #2 in October 2008 from another care home.

Her capacity level leaves her vulnerable and she has been assessed as unable to make informed decisions regarding her care. D1 has Power of Attorney; Case D has no insight into her condition.

She is typically alert in the morning and can sometimes be unsettled and calls out. She can sometimes answer 'yes' or 'no' although sometimes has incoherent and irrelevant speech. She has a tendency to talk to herself for long periods, but finds comfort in doing so and does not want to be disturbed otherwise will become irritated. She can be physically and verbally abusive. She is bewildered by everyday events and often shows signs of anxiety. She also shows signs of depression; she is withdrawn, cries and refuses to eat. As she has difficulty expressing herself she will bang on the table if experiencing pain. Staff must give her constant reassurance. She requires a high level of support to take part in activity programmes and to fulfil her social needs. She prefers to go to the church service at the care home on Thursdays and the priest visits her if she is unable to go that week. She frequently has trouble sleeping and requires support from two staff with night care. She cannot use the call bell in her room.

Medical and sensory conditions

In addition to her VaD, Case D suffers osteoarthritis and chest infections. She had pneumonia in August 2011. She has monthly GP visits for hypertension. She wears spectacles and two hearing aids. She has stage 3 chronic kidney disease. She is known for being reluctant to take medication.

Mobility and orientation

Case D's mobility is poor and she cannot weight-bear. When she walked she had a history of falls. Now she has contractions in both knees and is chair-bound. She has her own water-chair which has a lap belt to prevent her from falling out as she tends to lean to the right. She must use a stretcher if required to leave Care home #2 for appointments. Staff use an Arjo hoist with a yellow (small) cocoon sling for all transferring activities.

She experiences severe disorientation.

Her bed has an air mattress, bed-rails and bumpers. A Bed-Rails Assessment was completed in February 2013 because she could move a little and became confused and agitated while in bed. The consent form was signed by her family in May 2013. A slide-sheet is used to reposition her in bed.

Washing, bathing and skin integrity

Case D receives bed baths from two carers during which she is repositioned using a slide-sheet. She doesn't mind having male carers but can sometimes be physically aggressive when receiving ADL assistance. She is usually reluctant to wash, and if agrees to a bath will be unhappy.

A Waterlow score of 29 demonstrates that she has Very High Risk of pressure ulcers. Indeed she has a dry scalp and skin and is prone to skin-tears, so cream is applied regularly.

Grooming

She has her own teeth. However staff find it difficult to provide oral-care to her as she can become unhappy and resistant. She has regular podiatrist visits.

Dressing and body temperature

Case D requires support to get dressed, although may be able to say what she wants to wear if given two choices. She prefers to wear a blouse and skirt with a cardigan or dresses, and likes necklaces if in the right mood. She has no awareness of her body temperature so staff manage this.

Bathroom use and continence

Case D is fully dependent for her elimination needs as she is incontinent of urine and faeces. When she has soiled herself she scratches and digs down below so staff need to watch for this. She uses two types of continence pad; medium size for day and large at night. Catheters are not used. She is prone to UTIs. She suffers occasional constipation and has Senna tablets (laxatives) to prevent this.

Eating

Case D is 1.43m tall and has a thin build. Her weight has reduced since living at the care home and she was already underweight on admittance. At her heaviest she was 36.1kg and is now at her lowest of 30.4kg. As such her BMI has varied between an already underweight score of 17.6kg/m² and 14.8kg/m² (severe thinness). She has Ensure drink and Forticreme diet supplements to her diet to help her weight.

Case D requires full support to eat and drink. She now has a liquidised diet which she takes from a spoon. Her drinks are of normal consistency and do not need to be thickened. Sometimes she has a tendency to refuse meals or cannot be bothered to eat. This leaves her vulnerable to dehydration and malnutrition. She requires assistance to choose food but may be able to say 'yes' and 'no'. Indeed, she will not say if she is hungry but will reply if asked directly. She usually eats her meals in the lounge with the other residents but sometimes prefers to eat in bed. When she does eat she tends to swallow food very quickly without chewing so requires monitoring to prevent choking. The care plan for staff when providing feeding assistance includes making her comfortable and inform her she is about to eat, try later if she refuses or try porridge as an alternative to the meal. Staff should also encourage her to eat snacks between meals, particularly liquidised cakes.

End of life plan

A DNR Form was completed in August 2011. Case D has been assessed as unable to make her own arrangements regarding the end of her life.

Case E Stage One vignette

Case E is a female in her late 80s. She has AD which was diagnosed in 2007.

Pre-relocation

She was born in the same county and lived in the same town where Care home #3 is located, although did live in other countries for a while with her husband. She married in the 1950s but was widowed after 50 years of marriage. She has two daughters and three grandsons. In 2004 she moved to a sheltered flat because her garden became too much for her to manage. At home she had intermittent slow heart rate, a pacemaker fitted in 2004 and a history of fainting. She had bowel cancer in 2005. For 20 years she has followed an 'arthritis preventive diet' of no dairy, no citrus fruits and no red meat.

Relocation, capacity and care home life

She relocated to the care home in February 2012. Capacity information states that she has the capacity to make some uncomplicated everyday decisions regarding her care.

She always recognises her family but has occasional difficulty communicating with others. She can identify if she is in discomfort. She gets agitated and hits people with her stick sometimes as she thinks people are stealing from her. For example, after breakfast she believed that all the knives and forks were hers and became aggressive to those who she believed were stealing them. Therefore she requires staff intervention to manage her mental well-being, anxiety and behaviour. At one time she had Lorazepam (a sedative) in the morning as she kept telling other residents off and lashing out as if she wanted to fight. She also requires staff assistance to support her sexuality, privacy and relationships. She can participate in social activities and go on day trips, although the extent to which she receives support to do this is unrecorded. She likes a whisky at bedtime, and sleeps well.

Medical and sensory conditions

Case E visits a memory clinic for her dementia and takes, or took, Aricept for this. She also has diabetes and takes Clopidogrel, which inhibits blood clots. She visits an osteopath for her spine. She also has swollen feet and some leg discomfort at times, for which she takes paracetamol. Finally, she has a history of UTI so is encouraged to drink fluids. She is reliant on nursing staff at the care home to administer all medications.

Mobility and orientation

A STRATIFY falls assessment indicates that she is At Risk of falls. In June 2013, she was found on her bedroom floor having fallen while trying to put on shoes. She sometimes has help for transferring from carers but can walk with a stick.

She sometimes cannot find her room number but is generally oriented in familiar surroundings. She has a call bell in her room but forgets to use it. Her bed has a pressure-relieving mattress.

Washing, bathing and skin integrity

Case E requires either intermittent or complete support to wash. A bath hoist is used to assist Case E into the bath. She likes a bath at night at least once a week.

Very High Waterlow Pressure Risk Assessment scores indicate that Case E requires some staff intervention with skin care. Indeed, she suffers from leg ulcers that require dressing.

Grooming

There are some inconsistencies in the care record with regard to whether Case E wears make-up and whether she has dentures. She does not have sets at the hairdressers (located in a room in Care home #3) but does have her hair cut every four-to-six weeks. She has a podiatrist to trim her toenails.

Dressing and body temperature

Case E has a history of liking to be smart, clean and presentable at all times. She was known to be proud of her appearance and enjoyed accessorising with her watch and necklaces. She can choose the clothes she prefers and dresses herself sometimes. However carers should provide dressing assistance or monitor her clothing because if she dresses herself she will wear the same clothes day after day. Staff also monitor her because she has also been known to wash her own underwear and place it in her drawer while still wet. She may require some prompting to ensure comfort with regards to her body temperature.

Bathroom use and continence

Although generally continent, she can soil herself if she cannot get to the toilet in time. Therefore she wears continence pads held in place with net knickers. She prefers her own toilet instead of the communal ones. Although she typically can get herself up and locate her toilet, she is known to use sheets of toilet paper as a continence pad, so must be monitored. She has Senna tablets (a laxative) for constipation as and when these are needed.

Eating

The care record data on her height is inconsistent; she is either 5'2" or 5'4" tall. Her weight has increased since entering the care home. The last few measurements show she increased from 64.8kg in March 2013, to 75.6kg in May 2013 to 76.6kg in June 2013. Her BMI indicates that she is overweight.

Case E's diet has a normal consistency. She can feed herself although may need some assistance cutting food and opening cartons or bottles. In July 2012 a sore throat meant that she had problems swallowing. She had a pureed diet and thickened drinks until this improved a week later.

End of life plan

A DNR Form was in place from March 2012 (a month after relocating to Care home #3). She has been assessed as unable to make her own arrangements regarding the end of her life.

Case F Stage One vignette

Case F is a female in her early 90s. She has VaD which was diagnosed approximately seven years ago. Her last Mini-Mental State Examination gave her a score of 2/30 as she refused to answer some of the items.

Pre-relocation

Case F was born in a different part of the country to the care home. After joining the army in 1939 she met her husband in a hospital in Europe. She married in the 1940s and they lived in the same country as Care home #3. She has one son, F1, and one nephew. She is now widowed.

Relocation, capacity and care home life

Case F relocated to Care home #3 in March 2009.

Capacity assessments demonstrate that Case F can make every-day uncomplicated decisions. She was assessed as being able to inform others if she was being abused but because of her immobility would be unable to walk away.

Case F requires support to communicate her needs and maintain a safe environment. Staff must ensure that they eliminate other noises when speaking to her so that she can hear clearly. They are also told to explain procedures clearly and give her time to ask questions. She used to wake up early and was happy to chat to other residents throughout the morning. Now carers must provide assistance to fulfil her social needs. She is happy to have male and female carers. She does not display anxious or depressive behaviour. She likes to attend the religious services at Care home #3. Her sleep pattern is occasionally disturbed.

Medical and sensory conditions

In addition to her memory loss, Case F suffers from osteoarthritis, hypothyroidism, high cholesterol, diabetes (for which a blood glucose monitoring chart is completed often), and transient ischaemic attacks (TIAs). She has had angioplasty. She has glaucoma so staff must ensure she does not rub her eyes and keep her hands clean.

She has suffered chest infections and problems breathing, so has an inhaler. These can be linked to a history of smoking. Carers are instructed to ensure her bedroom is well-aired. She is usually breathless both on exertion and rest.

Mobility and orientation

There is conflicting evidence as to whether she is or is not at risk of falls. Although her STRATIFY assessment signifies that she is at Low Risk of falls, she wears hip protectors as a result of falling in the past. There are also falls incidents noted in the care record; in February 2012 she fell out of bed and sustained a heavy bruise to her face.

A handling risk assessment showed that she is fully weight-bearing but not able to walk. When she used to walk she used a three-wheeled walker with staff assistance. She also used to do balance exercises and keep-fit classes. Now she uses a wheelchair or two carers use a stand-aid hoist and large sling with Case F for transferring. A slide-sheet is used to reposition her when in a chair or in bed. The Emergency Evacuation Plan notes that she is too heavy for an evacuation sheet.

Case F can sometimes be oriented in familiar surroundings but would be unable to find her way back to the care home if she went out for a walk. She can find her bedroom. There are also environmental prompts in place, for example a red door for her bathroom. She can recognise family and friends.

Case F is at risk of rolling out of bed. Therefore her bed is kept at the lowest level and a mattress with sensor mat is kept on the adjacent floor during the night. She has a call bell. Her mattress is a pressure-mattress. One part of the care record stated that she must not use bed-rails because she could become trapped in them; however a bed-rail assessment in January 2013 said that they were to be used at all times. F1 signed a bed-rail consent form in February 2010.

Washing, bathing and skin integrity

Case F receives assistance with personal hygiene activities. Although she can wash the top half of her body, she receives help from one carer to wash the lower half of her body. She has a shower and hair-wash once a week. She is sometimes un-co-operative during personal care assistance.

Her Waterlow Pressure Risk Assessment signifies that she is at Very High Risk of pressure sores. Her urine and faecal incontinence can irritate the sensitive skin on her legs.

Grooming

Case F visits the hairdresser at Care home #3 weekly. She receives assistance with her nails and likes to wear nail varnish. A podiatrist visits her at the care home. Information about whether she does or does not wear dentures is conflicting.

Dressing and body temperature

Case F requires total support to dress and to regulate her body temperature, although she can verbally communicate her dressing needs. She wears hip protectors because of falls history.

Bathroom use and continence

Case F is doubly incontinent and so requires assistance with her elimination needs. Staff remind her to use the toilet regularly in an attempt to reduce soiling. She wears different pads for day and night; typically using three Maliform Plus during the day (absorbency 720ml) and a Maliform Extra at night (absorbency 960ml).

Eating

Case F is 174cm tall. Her weight has reduced from an initial 80.6kg on entry to Care home #3 to 77.7kg. Her BMI has reduced from 30.4kg/m² (obese) to 29.3kg/m² (overweight). Even though she has lost weight her Malnutrition Universal Screening Tool assessment shows she is at low risk of malnutrition.

Her diet is controlled to manage her diabetes. The consistency is normal and she does not have a problem swallowing. She requires prompting to eat but can feed herself. Sometimes carers need to cut food for her.

End of life plan

A DNR Form was completed in March 2012 owing to the likelihood of a poor quality of life in the future and after CPR. She has been assessed as unable to make her own arrangements regarding the end of her life.

Case G Stage One vignette

Case G is a female in her early 90s. She has AD, which was diagnosed either three or five years ago.

Pre-relocation

She had three sons but one died when aged 14. She has four grandsons. She lived in the local area with her husband but was widowed in 2012. At home she was very involved with her local church.

Relocation, capacity and care home life

Case G and her husband relocated together to Care home #3 in September 2011. He then passed away in January 2012.

She has fluctuating capacity. On relocation she was able to make some of her own choices and was happy to have support with decisions from her sons. A capacity assessment shows that she was unable to retain and weigh information about living at home and had a lack of insight into her condition. Her latest MMSE shows that her main cognitive problems are recall and language. Her sons are currently applying for LPA. Her safeguarding assessments shows that she is able to say if she is happy with the care she receives, able to inform others if she was being abused, is mobile and able to move away from potentially difficult situations.

Case G likes to be independent but requires supervision at times. She appreciates assistance and supervision to maintain her privacy and dignity. She can communicate her needs, likes and dislikes. In the morning she likes to stay in bed late and have a cup of tea first thing. She requires prompting and encouragement to fulfil her social and spiritual needs and mental well-being. She gets depressed and anxious intermittently. During her relocation she had insight into her condition and became depressed so was given antidepressants. She also had a traumatic experience in January 2012 when her husband became unwell, was transferred to the hospital and died the same day. She is not on antidepressants now. She exhibits some undesirable behaviour including complaining that she wants to go home; she is more likely to be in a low mood or confused in the mornings. She can take herself to bed. Her sleep pattern is generally undisturbed, although she prefers her bedroom door open.

Medical and sensory conditions

In addition to AD, Case G has osteoporosis and arthritis. She can identify when she is in pain. She also has her blood pressure taken frequently (during March 2013 it was taken four times per day but it is usually twice per week).

Mobility and orientation

Although mobile, Case G is prone to falls. Some falls are during the night and another was related to trying to open a door that was too heavy for her to manage. However she refuses to wear hip protectors. She sometimes does not believe the staff when she is told that she fell. She will need to be guided by one carer in an emergency. She does not use walking aids. No aids for moving and handling are used with her.

She is oriented in familiar surroundings. However she is not independent enough to go out on her own. She is sometimes upset when she can't remember the day or time.

Case G has a call bell in her room which she is encouraged to use but doesn't always remember to. She had a bed-rail assessment in April 2013 but these were assessed as not required at that time. She is unlikely to fall from her bed but has a sensor mat just in case.

Washing, bathing and skin integrity

Case G now receives assistance with washing and bathing. She sometimes refuses showers. Her Waterlow Pressure Risk Assessment showed that although she is fully mobile, her occasional urinary incontinence, age, oedematous skin (excessive amount of fluid around cells) and AD gives her a Very High risk of pressure ulcers. Her skin is becoming thinner so cream is applied regularly.

Grooming

Over time Case G required increasing supervision and assistance for shaving, nails, make-up, and oral-care. She has her hair set weekly at the hairdressing room and regular podiatrist visits.

Dressing and body temperature

Case G likes to be presentable and smart before leaving her bedroom. She can choose her own clothes and declined hip protectors when these were offered to her. In September 2011 she could dress herself; by February 2012 she needed assistance and supervision by one carer.

Case G has no problems with body temperature. She can say if she is too warm or cold and take action to meet her needs.

Bathroom use and continence

Case G is occasionally incontinent of urine. She wears continence pads day and night. She has no history of constipation or UTI. She can use the toilet by herself, and uses both her en-suite and the communal toilet. However she is encouraged to use the call bell in her room if she needs the toilet so that staff can ensure her safety.

Eating

Case G is 1.5m tall. Her weight has fluctuated between 56kg and 61.8kg. Her most recent BMI score was BMI 26.4kg/m² (overweight).

She eats a normal diet and her appetite is good. She can identify the foods she wants based on the menu list and normally eats lunch with the other residents in the dining room. Sometimes she prefers to eat breakfast in her room. She doesn't mind male or female companions during mealtimes. She can use cutlery and eat appropriately. She has some assistance with cutting food and opening cartons and bottles.

End of life plan

A DNR Form was completed September 2012, to be reviewed in September 2013. Notes on the justification for the order state that this was completed because Case G's AD means that her quality of life would not improve after CPR. It was also confirmed by her sons that she had previously stated (before cognitive deterioration) that she would not want to be resuscitated. She has been assessed as unable to make her own arrangements regarding the end of her life.

Case H Stage One vignette

Case H is a female in her early 90s. She has VaD.

Pre-relocation

Case H married her childhood sweetheart in the 1940s. Her son was born during World War II and her husband was killed in action while flying over Germany. In the late 1940s she met and married her second husband. She had one daughter in the late 1950s, several miscarriages and then a second daughter in the early 1960s, H1, (who is 20 years younger than her brother). The first daughter was killed aged eight years old in a road accident. There have been many other family tragedies throughout Case H's life. Case H and her husband adopted a daughter in the late 1960s. Case H also has many grandchildren and great grandchildren. Case H was widowed in the late 2000s after 59 years of marriage.

Case H's life immediately prior to relocating to Care home #3 is complex. In June 2008 she relocated to a care centre. However by December 2008 she was admitted to hospital following an aggressive incident for which she was sectioned.

Relocation, capacity and care home life

After her initial care home relocation and hospital sectioning in 2008, Case H moved to Care home #3 in December 2009.

Her main visitors are her son and biological daughter. Although her family members including nieces and nephews plus best friends and neighbours are on her Important People Chart, it is unclear the extent to which these individuals provided any caring activities.

She has been assessed as having fluctuating capacity to agree to receive care and difficulty retaining information long enough to make a decision. Therefore she can be vulnerable. She is bewildered by everyday events and suffers with severe disorientation. She can still use verbal consent (one or two words) for short conversation such as her toileting needs. Her family members are currently discussing LPA.

Case H has occasional difficulty communicating with others and her speech is sometimes incoherent. She requires a high level of support to take part in activity programmes and fulfil her social needs. She can be aggressive, unpredictable and challenging towards staff, for example she pulled one resident's hair and threw tea over another. She can also make false accusations of stolen money and belongings. She can often appear depressed, tearful and agitated, particularly after discussing the death or sickness of loved ones. She also used to search for family members. She was on Litalopram (antidepressants) once per day although it is unknown if she is still on this. She was unable to continue her last Mini Mental State Examination as she became tearful. Her mental well-being and subsequent behaviour is managed by successful interventions such as antipsychotic medication use, minimising her triggers and monitoring mood swings. She can be restless throughout the night, such as getting up to go into the lounge, so is monitored every 30 minutes.

Medical and sensory conditions

In addition to her dementia, Case H has arthritis in her right shoulder. She is sometimes breathless both on exertion and rest, so has an inhaler with a spacer twice per day. When she has a chest infection she can have trouble swallowing. A Grade 1 malignant tumour was found in her breast in August 2011. She has swollen lower extremities so staff must ensure that she elevates her legs when sitting in the lounge or in bed at night.

In August 2012 she fell and dislocated her left shoulder. This was repositioned in hospital. She can express pain orally or through her body language. She can have painkillers for any pain.

Her hearing is good but staff must speak loudly to her. She has spectacles to read and watch the television and has difficulty judging distances.

Finally, she is on long-term Quetiapine (an anti-psychotic) which cannot be reduced due to her behaviour. She does not self-administer medication.

Mobility and orientation

Case H used to have a walking frame but now finds it difficult to weight-bear and so sometimes uses a wheelchair. She has been able to stand up from her wheelchair with the aid of two care home staff and a walking frame. Carers sometimes use a stand-aid hoist with sling for transferring activities, especially when going to the toilet or commode. She has had some falls, linked to her inability to comprehend risk when standing up, and not asking for help. She shuffles her feet when walking.

She is disoriented to people, place and time.

Her adjustable bed is set at the lowest level and there is a pressure pad on the carpet next to it. Although a bed-rail consent form was signed by her son in 2010, the latest bed-rail assessment in April 2013 stated that these were not absolutely necessary. This is because she can climb on and out of bed so the greatest risk is that of injury if bed-rails were in place. When she is sleepy carers use the stand-aid hoist to transfer her into bed.

Washing, bathing and skin integrity

Case H receives assistance to get washed. She has a strip wash daily and a shower once a week. She can wash her face, upper body and arms but one carer must help with her lower body. She sits in a shower chair or commode to make washing and showering easier for her and the carer. She has not expressed a preference for the gender of the assistant. She is sometimes anxious during personal care so staff should explain the procedure beforehand. Notes state that they should offer her a cup of tea to encourage co-operation.

A Waterlow score indicates that she is At Risk of pressure sores due to her age.

Grooming

Case H needs help combing, washing and setting hair. She sees the hairdresser weekly. She receives full assistance by staff with her fingernails and a podiatrist visits to cut her toenails. Although she has loose teeth and sore gums she refused extractions and dentures from the dentist. Staff assist her with oral-care which she sometimes refuses.

Dressing and body temperature

Although in December 2010 Case H could choose her own clothes with prompting, by July 2013 she can no longer choose what to wear. She receives total support to get dressed. She typically wears loose stretch trousers to make toileting easier. She may sometimes refuse to change her nightwear. She also wears hip protectors in case of falls. Case H now has problems detecting her body temperature needs and acting on these. Staff therefore should monitor her closely for this.

Bathroom use and continence

Case H is doubly incontinent. She uses continence pads during the day and night. She can also use the commode. Staff monitor her stools using the Bristol Stool Form Scale in order to follow her

bowel health. For example, the day before the care mapping the daily record notes stated that she had a Type 6 stool. This could suggest: a slightly overactive colon, excess potassium in the diet, sudden dehydration or spike in blood pressure.

Eating

Case H is 1.62m tall. Her last recorded weight is 65.6kg, giving her a BMI of 24.9kg/m² which indicates a normal healthy weight.

She has Grade 1 fluid thickener in her drinks. She also requires a soft diet such as porridge, sandwiches or pureed food. She receives full assistance to meet her nutritional needs, but is not at risk of malnutrition. She does take calcium supplements, however.

End of life plan

A DNR Form has not been completed. There is a note in the care record dated April 2013 to discuss this with the family and GP. She has been assessed as unable to make her own arrangements regarding the end of her life.

Case I Stage One vignette

Case I is a female in her mid-80s. She has AD, which was diagnosed 11 years ago.

Pre-relocation

Case I's husband died just before she was diagnosed with AD. She then lived with her sister. She does not have any children but has a nephew, niece-in-law and their daughter as family.

Relocation, capacity and care home life

She relocated to Care home #3 in 2005. Her capacity level leaves her vulnerable and she is unable to make informed decisions regarding her care. She was unable to complete her last MMSE in March 2013 due to her poor communication.

Case I does not verbally communicate and struggles to understand others. She mumbles for attention and seems uncomfortable if she needs the toilet. She may respond to her name or laugh when spoken to. She is now bed-bound. She cannot participate in social activities. She exhibits active symptoms of mental ill-health and anxiety and is bewildered by everyday events. She requires staff intervention to alleviate this. For example, staff should ensure that music is always playing in her room to comfort her and use lemon swabs to moisten her mouth as required. In 2011 when she sat in the lounge she would pull up her skirt to express attention for an unmet need. She has a disturbed sleep pattern and may be confused on waking. At night she is repositioned frequently.

Medical and sensory conditions

In addition to her AD, Case I has heart problems, gout, depression, hypertension, Parkinson's Disease and epilepsy. She is prone to UTIs and is also deaf.

In November 2011 she had a large gastric bleed for which she was admitted to hospital. She was returned to Care home #3 on a palliative care plan and told not to return to hospital. Carers must check whether she has had a recent bowel movement before providing anti-constipation medication.

Mobility and orientation

Case I is now bed-bound. When she was more mobile carers used the stand-aid hoist with appropriate sling to sit her on a recliner in the lounge or into a wheelchair. Now she does not leave her bed. The stand-aid hoist is only used to weigh her. Therefore her STRATIFY falls score is 0 because she does not move. Carers use a slide-sheet to reposition her every two hours. She has no pain when at rest but slight pain on movement.

She suffers with severe disorientation.

She has bed-rails in place in her bedroom because although immobile she suffers from seizures and could fall. Although she doesn't understand the bed-rails she is not disturbed by them. At one time a Risk Management assessment notes that her legs were at risk of entrapment because an upper extension of the rails meant that the bumpers weren't covering the lower rail. This risk was alleviated by putting pillows either side of Case I's feet whilst new bumpers were on order. There is soft cushioning on floor but no use of a pressure alarm.

Washing, bathing and skin integrity

Staff provide bed baths to Case I. Her Waterlow Pressure Risk Assessment score signifies that she is at Very High Risk of suffering pressure ulcers. She requires complete support to prevent these and

manage her skin care (that is, turning every two hours with a slide-sheet). Carers apply aqueous cream and lavender oil to her skin after washing.

Grooming

Case I's hair is cut every three to six months. She requires full assistance with nail-care and a podiatrist visits every three months to cut her toenails. She does not wear make-up. Carers manage her oral-care.

Dressing and body temperature

Case I now only wears night dresses as she is bed-bound. She requires full support to dress. In 2011 the care record noted that she could make some clothing choices; now she cannot participate in choosing what to wear. She now has no awareness of body temperature and because of her frailty is vulnerable to changes in the weather.

Bathroom use and continence

Although doubly incontinent, Case I sometimes has Senna solution when required for constipation. She must be offered lots of fluids to prevent UTIs and constipation. She uses continence pads to manage her toileting needs.

In August 2011 she had a catheter which was to remain in situ until a pressure sore on her sacrum healed.

Eating

Case I is 1.46m tall. Her last recorded weight is recorded as 34.9kg. Her BMI is 16.3kg/m², meaning she is underweight and at moderate thinness.

She takes a pureed diet and drinks are modified with Grade 1 thickener. She also has Forticreme supplement drink to help her low weight. Full feeding support is given with meals. Notes from when she first relocated stated that she likes a hot drink before bed. However the most recent daily care record notes only typically recorded that she had been given breakfast; there were never recordings that she had been fed lunch or dinner.

End of life plan

A DNR Form was completed in September 2012. The justification was that her quality of life is unlikely to improve if a cardiac arrest occurred. Another note dated November 2011 stated that she should not be sent to hospital. She has been assessed as unable to make her own arrangements.

Case J Stage One vignette

Case J is a female in her early 90s. She has VaD which was diagnosed six years ago.

Pre-relocation

She married her husband in the 1950s and has three biological daughters and three step-children. The family lived in multiple European locations through the 1960s to 1980s until Case J was widowed. She then lived in a different part of England to her daughters. When older she moved closer to her daughters' shared house but she lived on her own, went by bus to the supermarket daily to buy food stuffs she needed and made her way by bus to appointments. However she then had a stroke. This led to a protracted, multi-hospital stay and subsequent relocation to a care home. She moved to Care home #3 after another long hospital stay.

Relocation, capacity and care home life

She relocated to Care home #3 in 2008. The decision to move to institutional care was made because her dementia led to increased confusion and inability to manage at home.

Her capacity fluctuates as she struggles to retain and understand information in order to make significant decisions. At times she still thinks that she lives in a previous home from her youth. Her cognitive and physical impairment also mean that she cannot walk away from danger. However she does hit back when hurt or feels threatened.

Case J requires support to communicate her needs and maintain a safe environment. She can become agitated and verbally and physically abusive. She sometimes hits others with her walking stick. She had poor scores in relation to recall and orientation on her last MMSE. As a result of the MMSE and aggressive behaviour staff are instructed to continue with orientation therapy, de-escalation techniques and one-to-one time to allow her to verbalise any concerns she may have. She only requires a minimal level of support to take part in activity programmes. She is generally independent with night care activities with some prompting. Occasionally her sleep pattern is disturbed and she has been heard talking to herself at night. She frequently doesn't get out of bed until late, and sometimes not until late afternoon or at all.

Medical and sensory conditions

In addition to her VaD, Case J suffers from TIAs, full strokes, hypertension, atrial fibrillation, Chronic Obstructive Pulmonary Disease (COPD), hyperlipidaemia, seizures and arthritis. She is an ex-smoker and uses inhalers to combat her breathlessness. She takes anti-depressants. However she is not suitable for Warfarin because of her dementia and high risk of falls. She is also allergic to penicillin. In September 2011 she made reference to hearing voices commenting on her activities so took Fluanxol (antipsychotic) for a while. The GP was also considering mirtazapine for low mood and appetite. She is sometimes confused but treated with antibiotics for UTI. She has been known to refuse medication, or refuse her morning pills but take her night ones. She has macular degeneration and wears spectacles.

Mobility and orientation

Case J can walk with a stick or a wheeled walking frame. Sometimes she forgets where she put her stick. She also uses furniture to maintain balance. Staff must supervise her when walking as she is at risk of falls; she was regularly found on the floor because she tended to become unconscious and fall. Staff know that when she seems vacant this is a clue that she might lose consciousness. She must wear well-fitting footwear and hip protectors with tailbone protector (HipSaver Quickchange brand) at all times, even at night. In October 2012 she registered for a wheelchair but the care record did not note whether this arrived. She requires physical assistance for transferring.

Conflicting data in the care record state that: she can be oriented in familiar surroundings or she is unaware of time, place and person. Disorientation makes her anxious.

There is a pressure mat sensor next to her bed at night as she does get up to use the toilet. Her latest Bed-Rails Assessment stated that they are not required as she can climb in and out of bed, although at times requires a little assistance. She will be resistive and angry if bed-rails are in place. Staff must ensure that her bed is set to the lowest level.

Washing, bathing and skin integrity

Case J requires assistance from one person with personal hygiene needs. At times she can wash her face and upper body with prompting. She enjoys regular baths but sometimes refuses to wash. She requires significant intervention by staff for skin care.

Grooming

She likes her hair washed prior to being set by the care home hairdresser. Case J is able to brush her teeth with supervision. She is regularly visited by a podiatrist for foot care, and the care home staff trim her fingernails.

Dressing and body temperature

Case J requires support to be as independent as possible when dressing and choosing clothes. She can generally express her body temperature needs although may require some prompting. That is, staff may need to directly ask her whether she is too warm or cold. They will also need to operate the windows in the lounge and her bedroom.

Bathroom use and continence

Case J is incontinent of urine. Staff regularly prompt her to use the toilet. However she finds it more difficult to get to the toilet because of mobility. Therefore staff place a commode next to her bed at night. She is prone to constipation for which she has laxatives when needed and staff also offer her massage to help her muscles relax.

Eating

No data on Case J's height were sourced from the care record. Her weight has varied since the relocation, but only by 2kg.

Because of her stroke she eats a soft diet. She is allergic to bananas. She needs encouragement and prompting to eat, but not always physical support. Staff must ensure she drinks plenty of fluids in hot weather.

End of life plan

A DNR Form was completed in September 2012. This was because professionals thought that she would not survive CPR. She has been assessed as requiring support in make arrangements regarding the end of her life.

Case K Stage One vignette

Case K is a female in her late 80s to mid-90s. There is ambiguity because there are two different birth dates in the care record. She has VaD.

Pre-relocation

As a child Case K was looked after by a different family to her biological parents but never officially adopted. She has a 'step-sister' who has her own son, Case K's 'nephew'. Case K never married. She worked as a mother's helper on a farm to a lady from the age of 15 for 67 years. The son of the lady she worked for (who is approximately the same age as Case K) is her main contact rather than her step-sister or nephew. On the farm she had a pet cat, budgies and farm dogs. While living in the community she was a member of the Women's Institute, liked TV, knitting, the Archers and holidays with her step-sister. She attended church regularly.

Relocation, capacity and care home life

She relocated to Care home #1 either in February 2007 or May 2011. Details are unclear in the record.

On entry to the care home she said she was aware of her rights but needed constant reminding of these. Capacity assessments show that her capacity level leaves her vulnerable and she is unable to make informed decisions regarding her care. Next of kin must be involved in complex decisions. She can make simple everyday choices. Advice to carers on helping her to make independent decisions include keeping eye contact, speaking clearly and slowly and eliminating background noise to gain full attention. However when helping her to make choices staff should avoid trigger points that could lead to upset and anxiety such as repeating questions.

She is visited by the aforementioned son of her employer who visits with his wife. Her step-sister also visits and sometimes takes her out on day trips.

Although Case K has some difficulty verbally communicating she can understand others' speech and gestures. She displays anxious behaviour. She can become quite tearful at times, for example twice in April 2013 she was anxious and crying before breakfast so was escorted back to her room and reassured. She thinks that other people who are making noise are shouting at her and that 'it is all her fault' and 'she is doing it wrong'. She is also frightened of male members of staff approaching her. She dislikes large open spaces and crowds and has gained confidence in smaller groups such as on the dementia ward. She also wanders, is agitated at times and displays other behaviours such as repeating words over and over. If she is depressed she sits quietly. Her mood can quickly change from hysterical laughing to tearful episodes; at these times staff test her urine for UTIs. Staff give encouraging and comforting words to her, or ask her if she would like to walk in the garden which she enjoys. She is comforted when she nurses her toy cat or helps to look after the care home's rabbits. Staff need to support her to participate in social activities; in April 2013 she joined in with a baking activity and mixed the batter with prompting. However her arm immobility meant she could not participate for long. She enjoys group activities and entertainment such as gentle exercise, singers and pantomimes but requires reassurance to enter the room because of anxiety. At other times she does not want to be in social situations and prefers to be alone in her room with her toy cat. She likes to dust her room and the dementia ward, and assists the housekeepers with their cleaning. She likes to lay the table before lunch. Occasionally her sleep pattern is disturbed. She has dreams about traumatic experiences in her life so requires reassurance.

Medical and sensory conditions

In addition to her dementia and anxiety, Case K has arthritis in her shoulder, hands and knees. She also has a bad chest and asthma and can suffer chest infections. Staff recorded an incident when she was bringing up a lot of sputum; she was encouraged to use a handkerchief but used her hands. She has hay fever in summer. Acute incidents in the care home include an infected open wound on her left leg that was treated with antibiotics and a sore lump on her arm. Staff are encouraged to observe her body language, facial expressions, behavioural and physiological changes for signs of pain. Her GP suggested in November 2009 that she had a mild learning disability.

Mobility and orientation

Over time Case K has been at No Risk, Moderate Risk and High Risk of falls according to her various STRATIFY scores. The latest score shows she is at Moderate Risk of falling. She can leave her room alone. She does not use equipment to walk, although staff must ensure that her path is obstacle-free. She does however use a wheelchair when on outings. She has occasional pain when at rest and moderate pain on movement. She does not need equipment for transferring although staff may provide some physical steadiness, and her arthritis may hurt her when standing. She can weight-bear.

However she can be disoriented so each door has a clear room sign. Staff must give her time to orient herself when she wakes up. She has been found in the reception area of the home after losing her way.

Her bedroom has a pressure mat at night to alert staff she is out of bed. She also has a call bell, which can sometimes use. The bell was removed in March 2013 but after a fall a month later because she went to the bathroom without slippers on, it was reinstalled.

Washing, bathing and skin integrity

At times Case K is usually able to wash her own face, hands and breasts but is less able if it is a 'bad day'. She receives support from a staff member with the rest of her body, whether a strip wash, bath or shower. On other days staff must provide full assistance with washing. She can usually choose whether to have a shower or wash. Case K must have female staff for hygiene activities. She needs to be prompted to wash her hands after using the toilet. Staff are to record if she refuses support or to have her personal hygiene needs met.

Her latest Waterlow score shows that she is at Very High Risk of pressure sores because of her dementia, tissue-paper thin skin, incontinence and tendency to sweat. She therefore requires some staff intervention with skin care. She has a barrier cream for her groin and sacrum. Staff need to use a barrier spray or apply a cream and talcum powder under her breasts after washing as the skin can become sore.

Grooming

Staff make appointments with the optician, hairdresser, podiatrist and dentist for Case K. She wears a full set of dentures which are soaked overnight. However on one occasion in the daily care record she couldn't understand how to take out her top dentures so wore them all night. She had a Hazardous Substances Assessment for Steradent (denture cleaning solution), which is kept in her ensuite. A podiatrist visits every two months to cut, file and clean her toenails. Her keyworker cuts and polishes her fingernails, and staff are encouraged to monitor her for sore nails as she tends to pick and bite them. Staff apply roll-on deodorant for her.

She wears spectacles. Staff need to ensure that these are cleaned daily and are in good condition.

Dressing and body temperature

Case K can choose her own clothes but may sometimes dress incorrectly, for example putting her shoes on the wrong feet. Therefore one staff member usually assists her to dress, or change if she has dressed incorrectly. She also has support because arthritis in her left shoulder makes it difficult to dress her upper body. For example with putting on a blouse, staff are instructed to prompt or support her to put her left hand in first when putting it on, and taking it out last when removing the clothing. When dressing carers must speak slowly and clearly, ensure her door is closed and put a sign on it for privacy.

She also requires some support to regulate her body temperature. She can say if she is too hot or cold if asked directly, and then encouraged to have hot or cold drinks if needed.

Bathroom use and continence

Case K is supported to use the toilet. Staff prompt her to go with simple communication but she sometimes refuses. She wears Tena Basic Comfort size 6 continence pads day and night, although is usually dry during the day. If she goes to the toilet on her own she sometimes forgets to replace her pad so staff need to monitor for this. Staff complete a Bristol Stool Form Scale to track the consistency of her bowel movements. She goes to the toilet twice in the night although may need to have a wet pad changed. The daily care record in May 2013 noted that she was able to use the call bell three times in one night for toileting. In one morning in May 2013 she was also incontinent of Type 6 faeces but this is not common for her. She sporadically takes Laxido for constipation.

Eating

Her weight has fluctuated but usually stays around 65kg. Her last recorded BMI is 27kg/m². There are no height data in the care record but using the weight and BMI this puts her height at 1.59m. This makes her very slightly overweight.

Case K sometimes requires prompting or encouragement to drink fluids and to eat. At meal times she may be sleepy at the table so staff will put food on her fork to prompt her to put it in her mouth. She may need prompting to choose appropriate cutlery. She has fluctuating ability to choose which foods to eat. She may sometimes need physical support to feed herself, and staff always provide assistance opening packets, putting toppings on toast and cutting food. This is required not only because of her dementia but her arthritis. Other days she can eat well on her own. She can recognise when she is full and prefers a medium meal at lunch and a smaller meal at supper. She is not at risk of malnutrition.

End of life plan

A DNR Form was completed in November 2012 because her frequent chest infections and dementia would be likely to make CPR unsuccessful. It would also be an undignified procedure for her to go through. She has been assessed as unable to make her own arrangements regarding the end of her life. The notes on her end of life plan advise staff to make her comfortable and pain free. They should provide regular oral-care and turn her every 2 hours so she does not develop pressure sores.

Case L Stage One vignette

Case L is a female in her early 80s. She has AD, which was diagnosed in 1999.

Pre-relocation

She was born and lived in the same county as Care home #2. Although the care record does not indicate when she married, she was widowed when aged 52. She has one daughter and two grand-daughters. She was able to stay at home for a number of years after her dementia and attended day centres. Had home she suffered from Bowen Disease (a type of skin cancer) and DVT.

Relocation, capacity and care home life

She relocated to Care home #2 in January 2011. Prior to this she had been living in a residential home since 2003. She moved to Care home #2 in 2011 because her dependency increased to require 24 hour nursing care. Her place at the care home is funded by the Local Authority.

Case L is unable to make informed decisions regarding her care and her low capacity level leaves her vulnerable. She is bewildered by everyday events.

Her speech is sometimes incoherent, and she is unable to express her needs through verbal communication alone or understand requirements of others, but may use non-verbal communication. Although often confused she smiles when spoken to. She experiences anxiety and likes to cuddles her doll for comfort. She generally has calm behaviour but can refuse or resist drinks, food and care. She requires staff intervention to manager her social activities and likes music and singing. Her sleep pattern is often disturbed but she will lie awake without talking. She requires support from two members of staff during night routines. Staff are asked to keep a lowly-lit lamp on overnight.

Medical and sensory conditions

In 2011, Case L took Aricept for her AD and was under the care of a psycho-geriatrician. She is reluctant to take medication. She has two upper and seven lower teeth left and no dentures. She hears well without a hearing aid.

Mobility and orientation

Case L is immobile. This is due not only to her poor balance when standing and sitting but her short attention span and difficulty following commands because of her AD. She has a water-chair when out of bed into which she is hoisted with a cocoon sling by two care staff. There are inconsistencies in the care record as to the size of the sling; black or yellow. She gets anxious in a hoist so some days she remains in bed. The water-chair has a pressure-relieving cushion. She is not in pain when at movement or at rest.

She experiences severe disorientation.

Her bed has an air pressure mattress with a Quattro overlay. A bed-rails consent form was signed by her family in January 2011. Her last bed-rails assessment was in April 2013. This showed that she is at risk of falling out of bed because although immobile she can lean to the side. Her bed-rails have a height-extension and normal bumpers. She is repositioned using a purple slide-sheet. In 2011 she could use the call bell but it is unknown if she can use it now.

Washing, bathing and skin integrity

Case L can become very anxious in a hoist due to experiences at her previous care home so rarely uses the bath with hoist at Care home #2. She prefers care by female staff.

A Very High Risk Waterlow Score signifies that she is at risk of pressure sores, mostly due to her incontinence which causes excoriated skin on her bottom. She requires staff intervention with skin care. She has a blow-up leg support to elevate her left heel because of a Grade 2 pressure sore.

Grooming

Carers wash her hair every week and she has it set every two weeks. She likes to wear earrings. Carers are instructed to pay daily attention to her fingernails.

Dressing and body temperature

Case L requires total support to get dressed. She has difficulty choosing her clothes because of her AD. However she likes colour-co-ordinated clothes so staff should take note of this. She has no awareness of her body temperature but can get hot easily and will look red in the face if so. She cannot request changes to the environment so requires staff intervention to control it.

Bathroom use and continence

She is both urine and faecal incontinent. She wears continence pads but is also hoisted onto the commode.

Eating

Case L is of 'average build'. Her weight has varied between 44.9kg and 57.7kg. Her BMI has varied between an underweight 17.9kg/m² to a healthy 22.2kg/m². Although height data were not in the care record the BMI and weight data indicate that she is approximately 1.6m tall. She lost weight at her previous care home, and Care home #2 successfully increased it. She takes a calorie supplement drink daily.

She eats and drinks well although may take a long time. Her diet is pureed as she used to chew solid food but forget to swallow. She requires encouragement and assistance so is fed by staff. She interacts well when dining socially and mirrors other residents so this is a good way to promote healthy eating. In 2011 she used a lightweight Melamine mug without a lid but a large handle; the care record does not indicate if she still uses this. She likes to watch TV while having breakfast. Her notes signify that she likes home-cooked British food.

End of life plan

Case L has been assessed as unable to make her own arrangements regarding the end of her life.

Case M Stage One vignette

Case M is a female in her mid-90s. She has mixed dementia; AD and VaD, diagnosed seven years ago.

Pre-relocation

She was born in a different area of the country to where she lives now. She also spent some of her childhood in India because of her parents' military careers. She was married in the 1940s and had two sons. She remarried in the 1950s and so also has two step-children. She was widowed in the 1970s. She has many grand-children and great-grand-children. She also has nieces and nephews who have their own children.

Relocation, capacity and care home life

In 2011, she moved to a care home as she found it harder to live on her own. The notes indicate that she became less and less able to cope there and in October 2012 fell and broke her hip. After she was discharged from hospital she relocated to Care home #2 for palliative care. She has many friends and family as visitors.

She has been assessed as unable to make informed decisions regarding her care. However she has capacity to make some everyday decisions and can communicate her needs. Although her perception is not always reasonable, her understanding is good.

Case M is aware of her memory loss. She can be agitated and aggressive, physically challenging and verbally abusive as the following examples demonstrate: 'she was trying to bite and hurt us (during a bed bath)', 'she punched a carer in the face (when applying cream)' and 'she bit her left arm and made it bleed and dug her nails in another carer'. She is then apologetic, and has even thanked staff and requested a kiss. Now all care is to be given by three carers at all times. In fact, from May 2013 a nurse was required to be present during all intimate ADL assistance as she is becoming frail and weak with chest pain, becomes breathless and looks pale. If so, staff are advised to leave the task for a while until she recovers.

Case M also requires prompting and encouragement to fulfil her social needs, support her mental well-being and manage behaviour. She is unable to make her own arrangements regarding spirituality. She often shows signs of anxiety and depression. She is independent in expressing her sexuality but may require some assistance to support her privacy, relationship opportunities and personal appearance. She sleeps well.

Medical and sensory conditions

In addition to her dementia, Case M has possible bowel cancer. The hospital refused a blood transfusion because of her dementia. She has a dynamic hip screw after her fall in 2012. She also has hearing problems.

She takes, or took, Galantamine syrup for dementia. She has a Ferrous Sulphate tablet for her haemoglobin level. When in pain she may have paracetamol. However she will tend to spit out her tablets when receiving medication. However if staff keep talking to her and gently give them back to her, she forgets she doesn't want them and takes them.

Mobility and orientation

Case M has occasional pain when at rest, moderate pain on movement and is breathless on exertion. She has a history of falls and is still at risk of these. In the past, two or more carers provided guidance and steadiness for transferring activities with a handling belt. She is now transferred with a turntable. She also uses a walking frame.

She is sometimes oriented in familiar surroundings. She remembers staff members but finds it difficult to remember where she is, recent events and the date. Carers should keep a clock in her view. She can recognise her parents from photographs.

Carers use a slide-sheet to reposition her when in bed. Her bed has bed-rails because she may attempt to get out of bed alone but needs assistance to stand; a consent form for these was signed by her family on her relocation. She also has bumpers on the rails as she kicks at staff. Her bed has a pressure mattress and compressor unit.

Washing, bathing and skin integrity

Case M receives bed baths. She sometimes refuses ADL assistance; her son has written a letter showing staff how to manage this behaviour. Carers are advised to ask her if she would like to wash herself. She has no concerns regarding the gender of her carers when receiving assistance.

A Very High Risk Waterlow Score indicates that she requires significant intervention with skin care.

Grooming

Her nails must be short and clean as Case M puts her hands in her knickers after defecating.

Dressing and body temperature

Case M is dressed by carers. She cannot express her body temperature; staff can tell by her position if she is cold.

Bathroom use and continence

Case M is incontinent of both urine and faeces. She can no longer recognise when she needs to evacuate so wears a full pad at all times. However she sometimes removes this. She is encouraged to use a commode first thing in the morning and in the evening before bed. Staff should check the state of her faeces using the Bristol Stool Form Scale. She takes Movicol for chronic constipation.

Eating

She is 1.62m tall. She has a thin build. The care record notes her weight in 2004 (pre-institutionalisation) as 48kg. However on entry to Care home #2 she was 35.8kg. Since then her weight had increased to 37kg, but has now reduced to 34kg. Her BMI is currently 12.9kg/m² (underweight with severe thinness). She is known to a dietician who prescribed three 30ml bottles of Pro-Cal Shot (manufactured by VitaFlo) per day. She also has one 220ml bottle of Ensure Juice (manufactured by Abbott) per day which gives her 50 calories and 20g of protein intake. She has Guinness twice a week to boost her iron levels.

Case M eats very little. For example, one day she ate only two spoons of her main meal and two spoons of pudding. She takes fluids well. Carers need to understand her behaviour as she will say "I don't want to eat this rubbish" but will then eat it. She has breakfast in bed, lunch in an armchair in the lounge, and her supper in bed. She requires support with cutting food and opening cartons and bottles, but otherwise can feed herself. Staff should leave biscuits near her as she loves them.

End of life plan

Case M is in Care home #2 for palliative care. She has expressed a clear wish to die. Staff from the hospice she is linked to visit regularly to monitor her. She has been assessed as unable to make her own arrangements regarding the end of her life. The care record contains a photocopy of her Living Will, signed 02/01/1996.

Case N Stage One vignette

Case N is a female in her late 70s. She has AD or VaD (the care record is unclear), which was diagnosed five years ago.

Pre-relocation

She was born in the same county as Care home #2. She married in the 1950s and widowed just before her 50th wedding anniversary. She has two children and two grand-children. She is a sociable person and enjoyed working as a child-minder. She likes most foods, listening to music, TV and reading magazines. She had a suspected stroke in 2006.

Relocation, capacity and care home life

Case N broke her hip after a fall down the stairs in her home in March 2012. She relocated straight to Care home #2 from hospital in May 2012.

Case N can be confused and bewildered by everyday events around her, although is often cheerful. She can have difficulty communicating her needs; her speech is frequently incoherent. She can understand others' speech or gestures. Staff should observe her for signs of pain and agitation: restlessness, facial grimaces, violent tremors or sudden screams. She can tolerate receiving assistance with ADLS only if carers engage her in conversation. She particularly enjoys talking about her personal photographs even if she cannot remember who they are of. Carers must provide complete assistance to maintain a safe environment for her, to manage her spirituality, sexuality and social activity. Staff must intervene to support her mental well-being as she can be anxious and has a history of depression. However she is now rarely tearful. She likes to participate in armchair exercises, reminiscence activity, games and the weekly church service. She has had some difficulties sleeping although now sleeps more soundly having settled in to Care home #2.

Medical and sensory conditions

Case N was on Aricept and Donepezil for her dementia. She also used to take Quetiapine for her mood but this has now been stopped. She has Deep Vein Thrombosis, osteoporosis, type II diabetes, hypertension, gout, rheumatism and hypercholesterolemia. She takes, or took, Almodapine, Bumetanide and Amloride medications for heart problems. She suffers chest infections but can be reluctant to take medication so sometimes goes without antibiotics.

Mobility and orientation

Case N requires two staff to provide constant guidance when mobilising as she is a high falls risk. She has not walked since her right hip hemiarthroplasty. She does not weight-bear and therefore will be unable to independently move away from immediate danger. She has a hoist with a sling for transfers and is hoisted onto her water-chair. Her head does not need to be clipped when hoisted as she has good neck strength. Her water-chair is a C5000/500 Hydro Tilt Manual Chair with a pair of C5042 HydroTilt lateral support adjustables, a C5038 HydroTilt Angle Adjustable Footplate, a C5036 HydroTilt Profiled Soft Headrest and three large adjustable 6.70002 Kinetic Balance Hip Belts. When these items arrived in July 2012 the care home's physiotherapist set up the equipment and advised carers on adjusting it as necessary.

Her orientation is poor. Staff are advised to orient her of the time and day every morning when she is washed.

She requires a long bed because of her height. Although her bedroom has an alarm bell, she does not use this appropriately; she sometimes presses it for no reason or has forgotten her need by the

time carers attend her room. She is at risk of falling while in bed; she leans to the left so must be cushioned on the left side. She also has padded bed-rails and a pressure mattress with compressor unit. She is repositioned using a slide-sheet to help avoid skin-tears.

Washing, bathing and skin integrity

She enjoys having a bath but is uncomfortable taking her clothes off in the presence of others. She must have only female carers. She may also become agitated during ADL assistance so the best action is to leave and return later. She can wash her face if given a flannel.

A Very High Risk Waterlow Score demonstrates that she requires significant intervention with skin care. Her skin is paper-thin and scars easily. She also has eczema. Staff cream her body after washing. She has no pressure sores.

Grooming

Carers encourage Case N to perform grooming activities for herself as much as possible. The care record notes advise staff to explain to her what they are about to do, not rush her and allow her time to perform the task. She can wash her hands if given a bowl of warm water and soap. Her nails must be kept short as she puts her hands in her faecal matter. Carers wash her hair.

Dressing and body temperature

Case N requires total human assistance to get dressed. She can raise both of her arms when asked. Staff ask her to choose the dress she would like to wear. She cannot always express her body temperature but carers know that she does not like to be exposed to the air.

Bathroom use and continence

Case N is doubly incontinent. She does not always ask to use the toilet but gets restless, so carers observe her body language to detect this need. She finds it difficult to open her bowels because of her immobility and her abdomen can be distended. She can be constipated and has been known to attempt to manually evacuate her rectum. She also has a commode but must be supervised when on it because of her falls-risk. She uses continence pads used although she has a tendency to pull her pad out. She now wears a slip with knickers over the top to prevent her from putting her hand into her faecal matter.

Eating

She is 1.77m tall. Her weight when she entered Care home #2 was 73.1kg but is now 84.8kg. This puts her at a current BMI of 26.8kg/m², indicating she is overweight.

Case N can eat and drink well although requires prompting because she can be distracted. She eats breakfast in bed, lunch in the dining room with the other residents and has supper in her room. She has a diabetic diet. She can choose what she would like to eat if choices are restricted to only two or three options. She uses a normal drinking glass and plate.

End of life plan

A DNR Form was completed in May 2012. She has been assessed as unable to make her own arrangements regarding the end of her life.

Case O Stage One vignette

Case O is a female in her late 80s. She has AD, which was diagnosed eight years ago.

Pre-relocation

Case O had a long career in science and education. She married in the 1950s and had one daughter. She has two grand-sons. She also has many nieces and nephews. She was widowed in the 1970s. She now does not remember her husband at all. She is a good cook, very artistic, loves classical music, animals, gardening and dress-making. She had an active and fulfilled retirement and joined walking groups, jewellery classes and the University of the Third Age.

Relocation, capacity and care home life

She relocated to Care home #3 in May 2008.

She has been assessed as unable to make informed decisions regarding her care. Her cognitive impairment makes her forgetful and confused, leaving her vulnerable. In March 2013 she could not complete an MMSE due to her poor cognitive abilities. Her daughter has Enduring Power of Attorney. Although she is unable to make major decisions staff must seek her consent at all times when offering any care or interventions.

She can go out on day trips with fellow residents or her family. Her daughter takes her for walks or to coffee. However she has been known to have an anxiety attack before going on a day trip so stays at home when this happens.

Case O has some impaired ability to communicate to others and to understand other's communication. Her speech is starting to get impaired with the progression of her dementia. She requires a high level of support to take part in activity programmes, to manage her behaviour and mental well-being. If she becomes aggressive her medication calms her down. Case O can take herself to bed but has a disturbed sleep pattern. If she is confused on waking, one carer can soothe her. Staff keep a light by her bed.

Medical and sensory conditions

Case O had been on Aricept and Memantine for her AD but these have now been discontinued. She takes, or took, Levothyroxine for hypothyroidism.

Mobility and orientation

Her STRATIFY score indicates that she is at Very Little Risk of falling. However she should not have mats or rugs in her bedroom. She can be mobile with little assistance although sometimes uses a walking stick. Carers do watch her when walking, however. She may need to be prompted for transferring activities but can perform the movements herself.

Case O has disorientation of time, person or place and fails to recognise and appropriately use everyday items. On 'good days' she can find her way around the care home and recognise her family and some staff. She could not leave Care home #3 on her own as she would not find her way back.

Case O had a bed-rail assessment in April 2013 which indicated that these are not necessary as she is independently mobile and at risk of climbing over the rails. However she has her bed set at the lowest level and has a floor mat sensor.

Washing, bathing and skin integrity

Case O requires complete support to wash and bathe. She can be physically aggressive during ADL assistance and hesitant to bathe or shower. Therefore she is encouraged to have a 'swim' once a week where possible. She prefers female carers and has the capacity to say no to uninvited sexual contact. She does not like to undress in front of other people.

An At Risk Waterlow score indicates that she requires some staff intervention with skin care. Her skin has sores where she scratches herself.

Grooming

Conflicting information in the record states that either: Case O goes to the hairdressers at Care home #3 weekly, or hates going to the hairdresser. She needs to be encouraged to brush her teeth.

Dressing and body temperature

The information on Case O's ability to dress is unclear. She can be resistant to changing clothes and will wear the same clothes for weeks. She dislikes nightwear so will sleep in her day clothes. She likes to wear trousers and socks at all times. She requires prompting to ensure comfort of body temperature. She hates to feel cold.

Bathroom use and continence

Case O is not incontinent. She can take herself to the toilet although has been known to refuse to go. She has also self-evacuated her bowels with her hands and inappropriately dispose of her faeces. Therefore carers must check her en-suite regularly and encourage her to wash her hands. They should also explain the side effects of her behaviour such as bleeding and pain. She takes prune juice to prevent the constipation that triggers the self-evacuation. If she appears more confused than normal staff must use a urine dipstick to check for UTIs.

Eating

Her last recorded weight was 59kg and BMI was 20.8kg/m². Her height was not indicated in the care record but this can be calculated as approximately 1.7m. Although she is a healthy weight for her height, the record notes that she has been losing weight lately.

She moved to a soft diet in April 2013 because she tended to spit out hard bits of food. She has Vitamin D supplements. She can feed herself although may require prompting. She likes food and can verbally communicate that she is hungry. However she needs to be reminded about mealtimes. She sits in the dining room with the other residents for meals.

End of life plan

Case O explained her wish not to be resuscitated after she was diagnosed with AD when she was cognitively healthy enough to make such an informed decision. A DNR Form was completed in September 2012. She is not to be sent to hospital if she becomes unwell. She has been assessed as unable to make her own arrangements regarding the end of her life.

Case P Stage One vignette

Case P is a female in her late 80s. There are no details on the type of dementia or date of diagnosis in the care record.

Pre-relocation

She married her husband in the 1940s. She has a complicated and tragic family history; after having two daughters in the 1950s, one died in the 1970s. She also fostered a child. She was widowed in the 1990s. She enjoys classical music, gardening, dancing, writing letters and reading books. In her later years she gave up doing things she enjoyed. She had a brain tumour in the 1980s. She also began to suffer diverticulitis 44 years ago. She had several TIAs.

Relocation, capacity and care home life

Case P relocated to Care home #3 in August 2004 because of a stroke she suffered at home the month before. She was also wandering and getting lost.

She was unable to complete an MMSE in March 2012 due to decreased cognitive abilities. She has been assessed as unable to make informed decisions regarding her care. She often resists assistance so staff should explain to Case P what they are doing to help her and why.

Her communication is now impaired. She cannot talk and is only able to make incomprehensible sounds. She may use non-verbal communication, however. She has difficulty understanding others. She requires a high level of support to take part in activity programmes and to fulfil her social needs. She has depression which is managed by Citalopran. She does not require assistance to sleep. In January 2010 she was found in bed with a pillow over her mouth and nose; from then staff now check her every 30 minutes whilst she is in bed. In March 2013 she was observed rolling with her head in the gap between the bed and side bed-rail. Now pillows block the gap and observation was increased to every 15 minutes to ensure her safety.

Medical and sensory conditions

In addition to her dementia and aphasia, Case P has deafness in her right ear because of childhood measles. She refuses to wear hearing aids. Her left eye also droops lower than her right eye as a result of a previous operation. In January 2012 she temporarily took a liquid form of Amoxicillin for swallowing problems. She experiences pain which may be the reason she is reluctant to get up in the morning. She has rectal paracetamol in the mornings before getting up and an oral paracetamol in the afternoon.

Case P has a high risk of inhaling tablets so medicine should be provided in liquid form or crushed into a thickened drink.

Mobility and orientation

Although Case P used to walk with the assistance of two carers, she is now less mobile. Her gait is also unpredictable so she stays in a wheelchair or wheel-able armchair. Two carers are required to use a hoist and sling for transferring activities.

Case P is oriented in familiar surroundings.

Her bed has an air mattress to alleviate pressure wounds. This is now on 'auto-adjust' as she spends more time in bed. In March 2010 a bed-rails assessment showed these were not appropriate as she would do her utmost to escape and be at more risk of injury. However in January 2012 she was

found with bruises to the right side of her face having collided into the wall next to her bed. From that point she had bed-rails with bumpers for protection.

Washing, bathing and skin integrity

Carers provide full assistance with washing and bathing. However Case P constantly displays resistant behaviour when receiving personal hygiene. She has a twice-weekly shower and bed baths or strip-washes on other days. She does not have a bath because she leans back and slides down. Staff use a slide-sheet with her during bed baths.

Her Waterlow score indicates that she requires staff support to manage her fragile skin. She developed a sacral score when she moved to a new recliner chair. She was put in bed while this healed and a pressure relieving cushion was added to prevent more sores. When her bottom is red she goes back to bed after lunch for a nap; this helps prevent sacral wounds developing.

Grooming

In April 2012 staff noticed Case P lost a crown and noted that although the nerve to the area would be dead the metal peg in her mouth may possibly cause discomfort or an ulcer. Staff were to monitor her oral health for this. Case P is known to hit out when oral-care is given or eye drops administered. However she must have her eye drops as infection would cause further pain. She has her hair washed once a week. She is visited by the podiatrist and goes to the dentist.

Dressing and body temperature

Case P receives full assistance from carers to dress. She particularly likes pink and beige clothes so wears these often. She wears hip-protectors. She has no awareness of her body temperature so requires staff support to control it.

Bathroom use and continence

She is doubly-incontinent. This is managed with a continence pad and net knickers. She will sometimes open her bowels if sat on the commode by her bed. She takes Lactulose regularly for constipation.

Eating

Case P's weight decreased from 49.7kg in February 2013 to 44kg by July 2013. She has a thin build. She takes a Vitamin D supplement to prevent reduction of bone density. There were no height and BMI data in her care record.

She receives full support to eat a pureed diet. Her drinks also have Grade 3 thickening fluids as advised by her GP because she coughed and spluttered on solid food and drinks of normal consistency. Carers suction her mouth as required if she chokes. She also takes Hyoscine Hydrobromide to dry up secretions in her lungs, nose and throat. She has drink thickener.

End of life plan

A DNR Form was completed in September 2011. She has been assessed as unable to make her own arrangements regarding the end of her life; there are notes in the care record for a specific funeral company who will deal with such arrangements.

Appendix 6: Stage Two case studies

Case A Stage Two case study

Case A is a female in her early 80s. She has VaD, which was diagnosed 7 years ago as a result of a stroke.

Cognition

Case A can make some decisions concerning her daily life, can read and verbally communicate although has a tendency to repeat conversations and questions. At times Case A is aware that she has dementia; however the quote below from her keyworker, K1A, demonstrates that she is not aware of the terminal nature of the disease:

K1A: She'll read things in the paper she's aware that she's got dementia to a degree...if she reads something that says oh you know nearly found a cure for VaD or for dementia she'll go oh I got that I'll be alright then... I'll be alright soon

This shows that she does not have full insight into the long-term effects of her condition. This is further support by K1A's anecdote about a time Case A was reminded of her diagnosis:

K1A: There was one lady that needed physical support with diet and I overheard the staff member say to [Case A] that "Oh she's got dementia so we have to help her" and the staff hadn't obviously been through the training yet and [Case A] went "Well I've got dementia and I don't need that sort of help" luckily it didn't affect her... she didn't see into the future that that could be her

Although she can verbally communicate currently, Case A's diagnosis could make her vulnerable and require support to remain safe. She confuses her life in Care home #1 with the delusion that she works there. This produces a wish some afternoons to 'go home'. Other times she believes she is at Care home #1 on holiday. When she is aware that she is confused, Case A becomes distressed and unsettled. She also suffers with anxiety, which is linked to her need to 'go to the shops to buy cigarettes'; in fact the carers look after her cigarettes to prevent her from smoking more than one at a time.

Family history

Case A was born in a different area of the country to where she lives now. She has four sisters: one who died a long time ago, one who lives in Australia, one who lives far away and has a mixed diagnosis of VaD and LBD, and a fourth with AD who died 18 months ago from pneumonia after a fall down stairs. According to A1 during hospital visits to the fourth sister Case A could not understand the situation:

A1: Mum would keep saying to me "I don't know what's the matter with her I don't know why she doesn't just pull herself together" she'd got no patience with her at all

Her VaD leaves Case A unable to interpret the reason for her sister's unresponsiveness. A1 also arranges sporadic telephone calls between Case A and her sister with mixed dementia:

A1: I get mom to phone her from time to time and I say you must tell her who you are because she won't know who you are and you have the bizarre conversations and mom just can't get it at all

However these conversations are rarely successful as the sister has impaired communication. The sister and family who live in Australia are frightened of developing dementia due to the family medical history.

Case A married her husband in the 1950s but was widowed in the 1970s. Her first daughter died at only a few months old from cystic fibrosis. Her adult daughter A1 has the same condition. Up until the mid-2000s Case A would have to get up early every day to help her daughter:

K1A: From the crack of dawn right to the last minute at night she's literally had to look after her daughter...so [Case A]'s always been you know been her main carer and then [Case A] also looked after her husband [who] passed away unfortunately but he was very ill and she nursed him as well and she's always done a lot of things for charities fundraising to make awareness of like cystic fibrosis

This demonstrates that Case A's life has been defined and shaped by her caring roles. She was dedicated to her daughter's well-being and survival.

Community life

Case A and A1 lived together during A1's first marriage. This was so that Case A could help with A1's health issues. After A1 got married a second time, Case A had a stroke. A1 witnessed her mother's stroke but struggled to get it diagnosed:

A1: We were both sitting in the lounge...and I just watched the whole of her left side drop down... I got a really close friend to come and take her to the doctors for me straight away and the GP said no she hadn't had a stroke but Guillain-Barre Syndrome and prescribed steroids... but then that night she was up all night doing strange things leaving the taps running shouting at me and I thought this is the stroke so the next morning I just took her straight back to the doctors said "This isn't what you said it is" they said "Oh perhaps she has had a stroke then perhaps you need to go to A and E"... they did a CT scan said "Yes she has had a small bleed"

A1 and her husband decided that it would not be appropriate for Case A to live with them as their house was geographically isolated from the surrounding local community. Case A did not want to be on her own, however, and wanted to live with her daughter. She moved into a ground floor flat about four miles from A1. It was on a bus route which enabled Case A to go into town and make her own choices about what to do during the day. The flat was classed as semi-sheltered; it had a travelling warden who visited weekly and a telecare alarm.

It was immediately apparent that the stroke had affected Case A's brain through changes in her personality and behavior. She left taps running, thought television noises were parties in her house and believed that if she entered television competitions that she would definitely win. She also began to have trouble using the telephone appropriately. She began to order items she didn't need from catalogues and on one occasion called a taxi company to take her to Heathrow so she could go to Australia and see her sister; a journey over 100 miles each-way. Over time she was perceived as unable to use the telephone without help.

A1 and her husband, under her GP's orders, stopped Case A from driving. Under law once a diagnosis of dementia has been made, the Driver and Vehicle Licensing Agency must be informed. When Case A did not remember why she had no car she would say that it was time for her to buy one. A1 learned the best way to cope with this:

A1: "Yes ok then mum we'll go and have a look shall we" because in her head she can still do all those things

This method prevented any further distress to Case A. At home she liked to read the paper and spend time with other residents in the flats. A1 had been worried that she would disturb the neighbours with her visits but in fact they welcomed her because they themselves were housebound:

A1: So they used to welcome [the] conversation even if it was the same sort of repetition

However she became a heavier drinker and re-addicted to cigarettes because of a neighbour's influence. She had stopped smoking previously because of her daughter's cystic fibrosis:

A1: Yes thirty-five years she'd packed up for and this alcoholic smoker persuaded her to and of course now she's forgotten that she ever gave up and it was a nightmare because I've got a chest problem and I used to go into the flat and it stunk it used to be so hot and the smell oh it was vile vile vile

Case A now smokes one or two cigarettes per day. This is discussed further in the 'Care Home Life' section later.

At home: medical and sensory conditions

Case A has arthritis in her spine, has had both hips replaced and at least one knee replacement. At home she also suffered with kidney disease, hypertension and spinal stenosis. She has never been on medication for her dementia. She has medication for blood pressure, cholesterol, and depression which she suffered after the stroke. Anti-depressants alleviated her aggression and anger towards A1.

At home: orientation

Case A began to misunderstand where she was and where her 'young daughter' was:

A1: She used to ring me up at night when she was in the flat and she'd be talking to me as [A1] the adult but looking for me as [A1] the child "[A1] [A1] I don't know where [A1] is she was in the bed with me... and you know how bad her chest is at the moment... she's not there and I don't know what to do what do you think I should do about it" you know which was heart-breaking

This was one reason for her institutionalisation and is discussed further in the 'Relocation' section below.

At home: mobility

After her stroke, Case A lost awareness of her left side and would bang her left shoulder when walking through doorways. This also manifested in other problems, for example although she wanted to continue ironing, she did not iron the left side of shirts because she had not perceived them. She would also only wash one side of her body, or only see food on one side her refrigerator. A1 explained that this is because of Case A's brain not perceiving one side, rather than physical issues such as numbness or eye damage.

Case A's ground floor flat had a telecare alarm with a pendant and pull cords in every room. She never wore the pendant:

A1: [It] used to hang beautifully on the rocking chair

A1 also perceives that Case A would never have used the pendant or pull cords in the event of an emergency. This was because Case A did not think she needed this technology, and the device was 'for other people'. However she did have a few falls in her flat:

A1: But she would never have thought to ring the bell she would have dragged herself over to the settee and sort of would wait for somebody to come... she just wasn't aware of it

Therefore this technology was redundant because: Case A could not remember it was there and if she had remembered it did not think it was appropriate for her. Other mobility-related technologies included hand-rails in the outside areas and in the bathroom by the shower and toilet. She used, and still does, a walking stick when she remembers to. This use of this device was due to her need to have a knee replacement; it was bought by A1 and is 'pretty' to encourage her to use it.

At home: washing

The only data on washing are that Case A did not wash the left side of her body and so was washed by carers. See the 'Informal and Formal Carer Assistance' section below for more on this.

At home: grooming

No data on Case A's ability to perform grooming activities were extracted.

At home: dressing

While at home Case A could initially remember that she needed to dress or undress herself and could perform the tasks to complete these activities. However she began to dress inappropriately as her VaD became more pronounced:

A1: It was the winter and she was wearing cropped trousers and a summer top and I said "Why on earth are you wearing that mum it's not warm enough" "Because Hello magazine says this is the ideal outfit to wear out this time of year long trousers are too warm and shorts are too short"

At home: elimination

Although she could remember she needed to go to the toilet and take herself there, she sometimes experienced continence accidents:

A1: I got called up there at two-o'clock in the morning and things like that to help her sort it out and I think it was just because she's on quite a lot of painkillers and sometimes they make her a bit dopey and she just wasn't aware of it... that was very very rare

A1 and her husband renovated the bathroom in the flat to make it more attractive when Case A moved in. Although Case A found the hand-rails around the toilet useful, she refused to have a full frame because her bathroom was small and 'it would spoil the look of it':

A1: I think I found it quite difficult to go from being the cared-for to the carer and because she is such a strong personality if she says "No I'm not doing that" or "I'm not having that" I would go with it whereas with hindsight I perhaps should have insisted... because it would have been better for her having raised toilets and things... because she is so strong I would just cave in

In the quote above A1 clearly feels that additional bathroom ATs would have helped Case A with toileting. However the barriers to this were a small room and lack of acceptance by Case A.

At home: eating

A1 began to suspect that her mother had problems with eating and drinking when Case A began to develop urine infections. She realised that Case A wasn't drinking enough fluids throughout the day, nor preparing meals:

A1: I'd make her a cup of tea when I went there in the evenings because I was there every night and had her every weekend but I realised that if I put a teabag in the pot it would be there the next day so she was going for long periods without drinking and she wasn't eating the food that's in the fridge because I was preparing it and you start to realise that something's not right

However she still loved to eat and drink and would consume meals if they were put in front of her. She knew how to eat and use cutlery. She used no eating or drinking ATs at home.

At home: informal and formal carer assistance

Pre-stroke and pre A1's second marriage, A1 and Case A lived together. A1 only conducted some IADL tasks with and for her mother. Typically Case A made breakfast and A1 made dinner and did food shopping. They shared housework. After Case A's stroke and relocation to her ground floor flat, formal caring staff visited her at home three times per day for a period of two weeks only.

A1: They came in to assess whether she was washing herself properly in as much as she was doing the left side as well as the right side whether she was able to toilet whether she was able to make herself a drink and snack and all those sorts of things

After the two weeks A1 performed these tasks with her mother but found it difficult to conduct any ADLs with Case A due to her own health problems. A1 then used her contacts within the healthcare industry to get her friend (an OT or Physiotherapist) to visit Case A's house. This professional did not assess the need for or provide ATs, but arranged for formal carers to visit regularly and for Case A to go to a day centre for activities and lunch on a Friday morning. However the day centre visits were only a 16-week programme; Case A then had to go to a different day centre twice a week which she hated:

A1: It was like an angry naughty child all the while because every week they would come to fetch her and nine times out of ten she would say her leg's hurting she couldn't go

A1 speculates that this was because the days were too long; 9.30am to 4.30pm, which Case A found boring and uncomfortable because of her arthritis. Case A was also unhappy with receiving regular formal care and kept cancelling visits, although eventually accepted their presence. These carers made sure that Case A took her medication because she tended to overdose on painkillers when she self-administered. This was because she could not remember if she had taken any medication to ease the pain from her arthritis. She had been found unconscious twice as a result. A1's husband then screwed a small safe with a combination code into a cupboard. It was screwed in to prevent her from taking her medication and hiding it as she had done with items. Case A was not given the safe combination code to prevent her from accessing her medication. Therefore only A1, her husband or the formal carers could access the medication:

A1: It was difficult because she felt that she was being treated like a child and she couldn't remember that she'd overdosed and whenever we argued she would always make it out to be my fault... of course I was doing it for all the best reasons

Over time the assistance provided by the formal carers became more intensive, from a tablet check to preparing Case A's meals and then to also watching her eat it. A1 bought microwave ready-meals for this to reduce the time, and therefore cost, of the carers. A1 described why she insisted on county council carers rather than agency workers:

A1: I insisted that they had to keep it in-house with the county council staff because I knew that those staff would be completely and utterly trained and that they would be getting paid to do the actual job rather than having to get their travelling time into their allotted time because I see a lot of carers who work for agencies and they're very good but in my opinion they don't have the same training... with county council... I knew she would get what she needed

A1 feels that her contact with formal services has been both positive and negative. Her health problems meant that she could draw on her previous experiences and knowledge when communicating with health and social care services. She was familiar with what could be available but still felt that it was an 'uphill struggle' to get information and assistance:

A1: The minute she had the stroke I then had to become her [carer] and I had lots and lots of battles not with mum but with doctors and other people because they couldn't associate the fact that I actually still needed care but I also needed to provide it to my mum

Case A was also under the care of a mental health team and had a case worker who was an OT. However A1 had a poor experience with the old-age psychiatrist at the mental health team after the diagnosis:

A1: She's got absolutely no people skills... I said to mum sit here I'm just popping to the loo I came back... she was trotting back out the consultancy door and she said "Oh she's finished with me now" I said "Has she we're going back in" she said "I just told your mum as I told you six years ago there's nothing we can do with VaD" I said "I don't care what you've had to say I've got a list of questions here and I've waited four months to see you and you're going to answer them"... she was absolutely dreadful... I asked for a referral to the mental health unit here to see what the doctor said and he was just so different... he said "Right I want you to shut up so I can talk to your mum" which is absolutely right that's the way it should be

Case A eventually became good friends with two of the ladies who provide formal caring for her; they continue to visit her at the Care home #1. A1 also found a neighbour to be invaluable support when she was too ill to care for her mother:

A1: She was our lifesaver if I was on holiday or if I was unwell she would always go in and make sure she was alright and get extra you know I would always go shopping for her and then she would go in and get extras and things like that

Relocation

Case A lived in the community for six and a half years after her stroke. She relocated to the care home in February 2012. A1 began to peruse care homes approximately a year before she made the decision for Case A to relocate to Care home #1. This was because her health-professional friend had

suggested she start to view care homes in case an acute event occurred, such as a fall, which necessitated a rapid relocation. Therefore, the friend suggested, A1 should find a care home she was happy for her mother to live in. A1 did this, although admits she still thought institutionalisation would never occur:

A1: I thought that we would still be able to muddle on but then she started running away from the flat because she suddenly stopped recognising it... she wouldn't get dressed because they weren't her clothes because she wasn't in her flat and I'd be getting phone calls at half ten at night "I don't know where I am this isn't my place I've not been here before"

Although she hoped that Case A's confusion was related to a treatable trigger such as a UTI, she eventually realised that the dementia was causing her mother's disorientation. A1 then made the decision for Case A to relocate after persuasion from others:

A1: People kept telling me she needed to go in a home GP kept telling me her best friend kept telling me her carers kept telling me... "You can't carry on like this you're gonna get ill... she needs to be somewhere safe now you can't not do something about it"

Indeed, the GP also used reverse psychology tactics to persuade A1 to make the decision:

A1: Mum's GP said "If you don't do something she's gonna have an accident and she'll be dead and how would you feel then and how would you feel if a family were involved as well it would be dreadful"

A1 had also put off making a decision until the GP told her to relocate her mother in case there were legal issues concerning forcing Case A to stay in a place she did not want to be. She felt that by having a health professional's support this gave an extra level of authority beyond her wishes. However A1 also experienced difficulties from formal services when asking for help locating and deciding on an appropriate care home because Case A was fully-funding:

A1: They just used to say "Look you're fully funding we have nothing to do with this" I said "Ok fair enough we're paying for it but surely you have a duty of care to support us and help us with this" "No only if we're paying for it" it was real hard work I kept thinking somebody somewhere should be able to help me with all this

Inevitably, along with the decision came negative emotions. A1 felt isolated, stressed, anxious and guilty:

A1: I felt a huge responsibility... I just felt like I was letting her down because she'd always been so good with me and absolutely dedicated everything to me I wanted to do the same for her and I also felt guilt-bound to do the same for her as she kept reminding me... it was horrendous

A1 and her husband also struggled to get Case A to perceive that she needed to live in a care home because she lacks insight into her condition and her ability to self-care. When the relocation occurred, A1 did not tell her mother that she was moving. A1 did not tell the formal carers about the plan as she did not want them to treat her any differently on the morning of the moving date. The strategy was for Case A's friend to take her out for the day so that A1 and her husband could remove her clothes and belongings from her flat and set them up in her new bedroom at Care home #1. Her

belongings included her rocking chair, bookcase and family pictures. A1 then fetched her mother from the friend's house and told her about the move. Case A was very understandably upset:

A1: [I] just said "Oh mum... because you've not been very well because you've not been recognising things we think it's best you come here"... she was absolutely livid putting it mildly "Well go away then now I don't want anything to do with you ever again how could you do this to me"

Indeed Case A was angry with her daughter for approximately six months after this. A1 found emotional support by the staff of Care home #1 and Valium from her GP valuable. Although it was a very hard time, A1 acknowledges that however the relocation had occurred, Case A would have been unhappy. Now, Case A believes that she may still eventually go back to her flat because she works at the care home and does not live there as a resident. Although sometimes A1 will 'go with it' and not tell her she is wrong, A1 has also at times told Case A that her flat has been knocked down by the council and she cannot return:

A1: Because she couldn't go back to it the council were going to pay for her to stay here because if she thought for one second she was paying she'd be straight out that door because she wanted the money to go to charity

This coping strategy appears to calm Case A when she discusses going home to her flat.

Care home life

Although her memory and speech have worsened slightly in the 18 months she has been in the home, Case A has expressed that she is now happier than she was when living on her own:

A1: She will say to me she's a lot happier now because she used to say to me in the flat sometimes "You don't realise what it's like for me here on my own you know hours and hours on my own waiting for you to come"

Case A also says at times that she likes Care home #1, particularly the people and the food. She sometimes feels happy that she has an easy life and is 'pampered' by the staff now that she is retired. This all helps A1 to feel that her decision to relocate was the correct one. A1 also feels relieved because she perceives Case A to have a better quality of life, is more stimulated, has more company and is safer than when she lived in her flat. A1 sometimes takes Case A out for lunch and to medical or social appointments. Case A also leaves the home on social activities and trips.

Case A smokes 1-2 cigarettes per day in the front or back garden and sometimes has e-cigarettes whilst indoors. Her keyworker 'K1A' believes that cigarettes help Case A to deal with her anxiety and to relax. She used to go outside on her own but now requires support and supervision from staff as she forgets to extinguish the cigarette properly. She also likes to be with them while outside for their conversation:

K1A: She often says "Oh you don't need to sit with me I'll be fine" but... because we don't want her to feel as if we are there because she can't manage we say things like that "Oh it's alright [Case A] I'm glad of the fresh air" and just pass it over to say we're glad of the fresh air glad to be out with her so it's her idea to drag us out of work even though we're obviously doing it for her safety

Carers are not allowed to smoke with her; those who don't smoke are not under obligation to sit next to her and can sit on another bench, walk around the garden or pretend to check the rabbits as long as she is in their vision. K1A speculated on what the policy might be if in the future Case A decides not to go outside to smoke:

K1A: It would have to be in her own room because you know the rest are communal areas and it's not fair [on] the rest... her smoke alarm in her bedroom would have to be changed... where's she gonna extinguish her cigarette... how long would the staff have to keep calling on her... does she have to have her window open... it doesn't mean that if you don't wanna go out and smoke you can't smoke because that's not that's not how we work and I believe that's how some people [care homes] are afraid to let them have a go

Care home #1 staff are willing to let Case A smoke, after a Risk Assessment, as it is her right to continue with this behaviour. A1 is happy that they are willing to support Case A with smoking, even if she would rather that her mother did not smoke:

A1: She's got a terrible cough but I've got to the point now where I think well she's eighty-two you know she's got a lot of pain she's got a lot to put up with if she wants to have one let her have one

Case A reads a daily paper, as she always did when she lived in the community:

A1: How much of it she actually takes in I don't know but she likes reading the paper so I think it's really important that we carry on with that

Case A does not have a telephone in her room because A1 fears that she would telephone the council to ask them to collect her and also have trouble understanding the dial-out codes to reach her daughter which would make her anxious.

Case A has a cuddly cat that gives her comfort. She has lots of memories when looking at old photos. She is generally able to sleep well although the activities that form her night routine require some support. Her bed call-bell is always kept within reach of her at night.

Care home: medical and sensory conditions

In addition to her VaD and previous medical conditions, Case A now has osteoporosis and is prone to UTIs. She has painful knees, shoulders and legs because of arthritis and has laser acupuncture and Movelat gel applied to alleviate this. She is under the care of an old-age psychiatrist and takes 30mg Atalopram daily for depression. She has no problems with her hearing but has cataracts and wears spectacles. She has annual eye tests.

She is happy to go for health appointments and have tests and scans as long as the procedures are explained to her. A1 hypothesises this is because Case A is familiar with hospital environments due to her life history. She is fully dependent on staff for administration of medication and is sometimes reluctant to take it.

Care home: orientation

All doors in the dementia ward are labelled to help Case A orient herself and she has learned that, for example, the light blue door leads to the shower room. She can also use labels in the kitchenette to put away items when drying up. Despite this she still has some disorientation to place. For

example some mornings she'll wake up and she'll think her en-suite bathroom is the kitchen. Case A is usually predictable in her disorientation:

K1A: She'll always come out of her room and turn left and you say "[Case A] the kitchen's right"... if [Case A]'s got an option she'll always turn left if you watch and observe her if there's many ways that she can go she'll always go left

K1A believe that Case A always turns left because of her VaD rather than physical damage after her stroke. This is important to understand her wandering behaviour.

Case A's disorientation regarding time largely occurs in the afternoon. Care home staff observed that she became most anxious and distressed between three and five o'clock in the afternoons. They discovered this time corresponded with her daughter's afternoon cystic fibrosis therapy; and as she believes she works at Care home #1, that her shift has finished. Staff at these times use distraction techniques such as social activities or having a cup of tea to help her anxiety.

Case A also has some disorientation to person. She sometimes believes that Care home #1 is K1A's house and that K1A sleeps there at night. K1A is happy for Case A to believe this if it comforts her and makes sure never to say goodbye to Case A when her shift finishes. She lets Case A know that she is not going to be around but not that she is leaving the building and she never uses the word 'home'. K1A tells Case A that she is going to sleep in her room and that if she wants K1A just to use her call bell. This would of course alert the on-shift staff, who Case A believes works for K1A. However her delusion at times has led to difficult situations:

K1A: She said "Oh you know just get [K1A] [K1A] will know what I want... it's a drink but it's not a drink you can drink it but it's not a drink you usually put it in another drink" [laughs]... they said they ran through different things and she said "Oh it comes from a cow... [K1A] knows where it's kept just wake her up and ask her where it is" because she just thinks that generally I'm just in charge and it's my house... but obviously it was only milk so they just said "Oh we won't wake her up for that we'll get into trouble" and they just sort of go along with the fact that she just thinks that I'm in charge

As she lives locally, K1A has said she is happy to be telephoned or called in if Case A wants her although this has not happened yet. Staff usually find a way to alleviate Case A when she requests K1A's presence. This works because the staff meet regularly to discuss residents and are all aware of Case A's delusion:

K1A: It's important that we're all singing off the same hymn-sheet... because otherwise it's just not gonna work you know if someone turned around said to [Case A] "Well [K1A] doesn't sleep here she's gone home"... she would just become anxious the fact that it's dark and she's not sure and "Well if [K1A]'s not here I'm not supposed to be here" and things like that... so it's to enable her to have a good night's sleep these are things that we necessarily have to put into place... the extra anxiety and the stress just doesn't do their health any good

Staff and A1 also 'play along' with other time, place or person delusions Case A may have, for example:

A1: I don't challenge her on it she'll say "I've done my washing this morning and hung it out" "Oh have you mum that's nice"... as long as she's happy and safe that's all I care about

Case A is known to wander up and down the corridors; all outside doors are alarmed.

Care home: mobility

Although not At Risk of falls according to her STRATIFY score, Case A occasionally needs support from carers when standing and sitting due to balance and pain in her knees. She does not require a stand-aid hoist for transfers. Her balance when sitting is good. Staff have recently noticed that she sometimes becomes breathless on exertion. She has a stick for walking but forgets to use it or refuses to because she believes she does not need it:

K1A: Her daughter brought her a prettier looking stick so it's got like the flowers and you know it's a pastel one so it doesn't look like a horrible wooden stick... you can give it to her and say "Oh you know [Case A] here's your stick" "I don't need that" and you're like "Well you know we're going outside anyway so why don't you" and she'll take it off you... she just needs the reminder to use it

K1A also perceives that because there are grab-rails on the dementia ward Case A feels that her stick is unnecessary. She particularly forgets her stick when anxious to go outside for a cigarette:

K1A: When she says she wants a cigarette she doesn't want it in five minutes it's now it's like something's clicked to remind her she smokes or she needs one and that's when she has to go

Yet if she was having an afternoon whereby between three and five o'clock she was distressed and getting ready 'to go home', she will never forget her stick. K1A believes that this may be because she remembers that 'home' is a long distance and she needs to get to the bus stop safely. She has fallen when walking too fast. She used a walking frame after her hip and knee replacement surgeries and does not want to use one now. Her GP suggested a wheeled trolley but A1 believes that this would be riskier for falls as Case A would not remember to use the brake. Case A does not use a wheelchair when she goes out with her daughter because A1 would not be able to push her. They only walk for short distances together.

Case A's bedroom contains a low divan bed to enable her to transfer into it more easily. She had a bed-rail assessment in February 2013, but does not require them as she is at low risk of falling out of bed.

Care home: washing

Case A is able to shower herself independently but staff are there to supervise her for safety reasons and provide some prompting or assistance with her lower extremities. Carers also move the shower head away from her when it first comes on so that she is not under very cold water. She can operate the shower by reading the simple instructions. The room has non-slip tiles with special grip and grab-rails. Case A prefers a daily shower but on occasion will have a bath when her arthritis makes her legs painful. On these days she uses a mechanical bath to alleviate her pain:

K1A: The seat of the bath actually comes right out so [Case A] can sit on that and then it's controlled by a remote to lift her up and into the bath and she just stays remaining on that seat

The chair is slow-moving, has arms and a lap belt. Case A is happy to use the mechanical bath and has been known to comment that it is a 'good invention and that she should get one for her house'.

This may be because the mechanical bath is not on the dementia ward but in the main part of Care home #1; Case A may then believe that she has gone into a stranger's house to have her bath. Skin integrity assessments have shown that Case A is at very high risk of having pressure sores. Therefore she is encouraged to keep mobile and not sit for too long.

Care home: grooming

Case A has her own teeth. She can perform oral-care activities but sometimes requires prompting. She has a notice on her mirror reminding her to brush her teeth twice a day:

K1A: It does work you know when she looks into the mirror she sees it but [Case A] can sometimes look at things and completely not see them at all

She may also be verbally prompted by staff or they may leave her toothbrush with toothpaste on it for her to see later. Otherwise she can physically brush her teeth independently. She uses an electric toothbrush to make this activity easier. The staff keep this charged for her because she would just put it in the basket rather than on the charger. She visits a dentist with A1.

Carers must ensure her nails are clean. A podiatrist visits regularly to take care of her feet. Case A also requires help to blow-dry her hair but is happy to have help with this because she likes to feel pampered.

Care home: dressing

Case A requires minimal assistance with dressing. Although her physical function is generally good, she always receives help to put on undergarments. This is due both to her arthritis in her shoulders and because she now gets breathless on exertion. Her cognition with respect to dressing fluctuates; she is able to choose her own clothes but perceptions of A1 and K1A concerning whether she understands how to co-ordinate clothes are contradictory. Case A may also sometimes put clothes on incorrectly and be reluctant to wear new clothes that A1 has bought for her:

K1A: She'll say "Oh that's not mine"... you have to remind "Oh [A1] brought it" "Oh yeah I remember" and then it'll come back [although] whether it comes back completely yet we don't know... because she gets a bit embarrassed about her memory loss so whether it's her way of saying oh yeah I remember but she doesn't I don't know

She may need to be encouraged to change clothes as she may wear items for multiple days. She has problems perceiving laundry as dirty even if there are visible marks and may be reluctant to change when it is suggested. As such carers have put a sign in her en-suite reminding her to put dirty laundry in her linen basket; this works for wet flannels and towels but is not as effective for clothes. She can manage her body temperature but if leaving the care home needs reminding to wear a coat.

Care home: elimination

Case A is usually able to locate her toilet. She will only use her en-suite toilet rather than the communal one in the shower room:

K1A: She won't ever go to that she knows that her bedroom's the one with the blue door and she knows that her en-suite's on the right side as you walk in

Her en-suite has a raised, winged (with chair arms) toilet seat in her bathroom; this helps her mobility which is impaired because of arthritis. The seat is white because Care home #1 could not

obtain another blue one like the one in the communal bathroom. When K1A asked Case A how she felt about her toilet seat Case A had not noticed its presence, but likes the frame around the toilet.

She is not incontinent and can detect when she needs the bathroom. She requires one laxative drink per day for constipation. She does not like the taste so this has to be mixed into orange juice.

Care home: eating

Her height is 152cm and her weight is 70.7kg, translating into a Body Mass Index of 30.6kg/m² (obese). She is at low risk of malnutrition. She must be encouraged to drink plenty because of possible UTI risk. As such A1 ensures that the mini-fridge in Case A's room is always stocked with non-alcoholic beer, and the top drawer 'tuck box' in her room is stocked with snacks. This is because although in the evening Case A would not think to prepare herself a squash or water, she would think to get herself a beer. This ensures that she intakes enough fluids.

She eats and takes fluids well, although at a slow pace. According to K1A, Case A can use cutlery successfully. However A1 noticed that Case A uses a knife incorrectly quite often:

A1: [Instead of] having the serrated edge down she'll often have the smooth edge down say "Oh mum you've got your knife round the wrong way" "Oh yes I keep doing that I don't know why"

A1 has also seen Case A struggle to cut food because of her arthritis. She does not like waste so will usually eat food even if she does not like it. The carers always ask residents for their menu choice in the morning but kitchen staff send down both choices:

K1A: They send both choices down because people with dementia wouldn't remember what they ordered a few hours before... and they visually look at it to see which one they prefer... then they're given the options of whatever the vegetables are which ones they like on their plates

Case A's meals are typically plated up by staff although Case A can put her vegetables on her plate. She usually chooses for the staff to do it because, in her own words, she 'likes to be lazy'. However she can make herself, and others, a cup of tea and prepare snacks in the dementia ward kitchenette. She has had a Risk Assessment for the kettle which is a special device with boil-dry protection which means that it will not work without water inside:

K1A: What was happening was that [Case A] was switching on the kettle but not filling it up with water... she was forgetting that method so we had to buy a kettle that switches off without water in it because otherwise it will melt the elements and could potentially cause a fire

K1A had heard about this kettle and discussed the possibility of its use at the company's Head Office. With their blessing she sourced and bought the item. Staff usually remember to keep the kettle filled with water for Case A's use but by having a boil-dry kettle they know they are safe. They also keep a note by the kettle with tea-making steps so that she can remember what to do. They have placed a dish by the kettle for her used teabag so that she does not need to walk to the bin with it and cause a slipping hazard. If making tea for others she will forget their sugar because she does not take it. A1 believes that Case A's ability to make tea is 'amazing' considering Case A would not make tea when lived in her own flat.

The kitchenette cupboards are labelled so that she can find her snacks and understand where items are. The kitchenette also has an oven for residents to use with staff supervision. The electric switch is hidden so that residents cannot turn it on unsupervised:

K1A: They can mess with the knobs all they want to but the actual switches to turn the electricity on are hidden

She is sometimes reminded to come to the dining room for meals. On one occasion in May 2013 she ate salad cream believing it to be yoghurt. Although she is not allowed alcohol because of her pain medication she has non-alcoholic beer some evenings.

Care home: family visits

A1 visits Case A every weekend and every Wednesday, when she is not at work. At times A1 will take Case A out to the shops, back to her house, to the hairdressers or beauty salon. Case A loves to shop, but her dementia can cause some problems:

A1: She'd buy absolutely everything... it doesn't matter what style it is if it's an eighteen she picks it up and she likes it... so sometimes we'll just buy them and [I will] take them back the next day... I say "I'll take it home to put your name on because you don't want other people taking it do you when you're at work" "No no no" so she's fine with it so then if she doesn't need it or it's not the right size I just take it back then because it's easier

A1 found this to be the best method of coping with her mother's shopping habits, rather than stopping her mother from buying the item while in the store.

A1 has been involved in some of Case A's ADLs before; sometimes helping to shower and dress her mother if she has visited on a day when Case A wanted to stay in bed for longer. They do not use any technologies for these activities. A1 will also manicure her mother's fingernails. A1, like all family members of residents, is involved with decisions about Case A's care and the plans for care. The care home conduct annual care plan reviews with family members to discuss if anything needs to change.

Case A is also visited by two friends who lived local to her when she was in her flat. They usually sit in Case A's room or the garden and have a chat over coffee. However Case A has been known to confuse her living situation on their visits:

K1A: A couple of times [Case A] has said to them "Oh I'll come home with you then" especially in the earlier days of [Case A] living here but you know it's easily evaded by discussing other things

Her friends also like to join in with activities in the home such as Care home #1's annual fundraising fete. Friends only take Case A out of the home on trips or appointments when A1 is on holiday. They will use a wheelchair for this, something that A1 could not do because of her health. The wheelchair can easily be borrowed from Care home #1.

Care home: end of life plan

A DNR Form was completed in September 2012. Case A has been assessed as unable to make her own arrangements regarding the end of her life. Her notes on palliative care show that the environment should be light and airy as she is frightened of the dark.

Case B Stage Two case study

Case B is a female in her mid-90s. She has VaD.

Cognition

B1 first noticed signs of Case B's dementia when IADLs such as balancing her chequebook became difficult. Case B then had an MMSE but scored:

B1: Nineteen out of twenty or something like that

This is inaccurate in relation to the real total potential score for the MMSE of 30, but nevertheless indicates that at the time Case B was not considered as having dementia. However later that year, after moving into her first care home, she had a brain scan due to her behaviour: trying to leave at night-time, wandering into other residents' rooms and leaving taps running. She was also usually disoriented; B1 suspects this is because she had been in and out of hospital due to falls. Following diagnosis, her first care home stated they could not meet Case B's needs.

When Case B entered Care home #2 she had the capacity to make some uncomplicated everyday decisions regarding her care and was able to communicate with staff, although staff were advised to speak clearly and at eye contact level. Now, her capacity level leaves her vulnerable and she has difficulty communicating.

Family history

Case B married her husband in the 1940s but is now widowed. She has one daughter, B1, two grandsons and one great-grandson.

Community life

Case B did not live at the same house as B1, as was indicated in her care record (this may have been recorded as her immediate prior residence was her first care home). She lived in a first floor flat which she and her husband moved into in the 1980s, to be geographically closer to B1 and the grandchildren. She remained living there, post-widowhood, until she was in her mid-to-late 80s. The flat had two-bedrooms, a living room, bathroom, kitchen and open access to the stairs; were she to become disoriented there was a real risk of falling down them. Eventually she began to show some trouble with housework and conducting IADLs appropriately:

B1: Up till towards the end it used to be very tidy and organised ... but she stopped putting things away properly and she just put them in the nearest drawer and she didn't always know if she'd paid her bills or not she didn't write it on the calendar

She could not select the right items for her shopping list and would build up a lot of some items but run out of others.

At home: medical and sensory conditions

Case B has osteoporosis, poor sight and impaired hearing for which she has spectacles and hearing aids. She suffers migraines, or as B1 suspects, mini-strokes (TIAs). At home, although Case B had a medication dispenser which had been recommended by her GP, B1 still worried that Case B was not taking the right tablets at the right times.

At home: orientation

At home Case B began to show signs of disorientation and once telephoned B1 at five o'clock in the morning enquiring about the time.

At home: mobility

Case B began to suffer impairments in her gait:

B1: She was very bent... looking at the ground all the time

When she made tea for guests she could not carry the cup and saucer well. To help her walk when outside she used a four-wheeled walking frame with a basket to hold shopping and personal effects. It also had a seat if she needed to rest. B1 cannot remember where Case B acquired this item but remembered that Case B had catalogues advertising AT and other environmental aids, although does not remember the name of these or where they were sourced. B1 feels that Case B was reasonably good at knowing what was available because she was keen to perform ADLs alone as long as possible.

Case B began to have falls at night, possibly because of TIAs. B1 believes that Case B may have fallen down the stairs on one occasion. She had a pendant to call for help when she fell, which alerted an ambulance and the neighbours. She had this device for two to three years, provided by the county council after Case B contacted them. She paid in instalments for the device and for continued call-centre communication. She was positive about having and using this technology as it helped her to feel safe. Case B's neighbours helped her whenever she fell but, according to B1, were getting fed up of helping as this occurred once or twice per month. She was not abusing her pendant, however; these were valid cries for help.

She had a small step-ladder for use in the kitchen, but B1 found her 'flat out' having fallen off this. B1 also found very old food packets on the top shelves when she cleared out the flat; Case B was either cognitively unable to perceive the need to check her cupboards for out of date produce or physically unable to reach and clear them.

At home: washing

For a while Case B occasionally went to an Age Concern day centre and had a bath there. She then had a bath lift installed in her flat to help her get in and out of the bath. She first stepped into the bath herself, sat on the seat and it then lowered her into the water. She got the device out of the aforementioned catalogue and it was:

B1: Fairly expensive [the device and the fitting fee]... so we tried to decide what to do with it when we sold the flat and in the end we had to give it away... because they didn't want it here [Care home #2] for example

At home: grooming

Case B visited a foot clinic regularly. She had no disability with grooming activities.

At home: dressing

Case B coped with dressing tasks when she lived at home.

At home: elimination

Case B was continent and was not impaired when using the toilet while she lived at home.

At home: eating

Case B had a gadget for unscrewing jam jars; B1 now owns and uses this. At home Case B ate very well and could use cutlery without impairment.

At home: informal and formal carer assistance

When Case B lived at home, she had a cleaning lady twice a week. This woman had originally visited once per week but Case B perceived the need for more help. As Case B began to suffer mobility impairment B1 began to do her mother's shopping for her; either at the supermarket or online. The deliverers would bring the food up the stairs to her flat and even put it in the cupboards and fridge-freezer for her. Typically Case B gave B1 a list of the foods she needed:

I: Did you have to sort of check round the house and make sure the list was actually accurate first?

B1: I didn't really get round to doing that I mean I probably shoulda done towards the end because you know you'd find she'd got three weeks supply of tomatoes and cereal

Although there were some problems with this, Case B was not malnourished. B1 did not perform any intimate activities for, or with, her mother; but contacted formal care services when she perceived Case B to require assistance with dressing, washing and provide regular supervision. However there were difficulties with getting Case B to comply with the care plan:

B1: I tried to get a carer to come in the mornings that the cleaning lady didn't come in... we started it off and she agreed she wanted one and then after someone had come for a week or two she told them she didn't need them anymore [laughs]

B1 did not know about this until an incident whereby Case B was admitted to hospital with a nosebleed:

B1: I said "Wasn't the carer there" I phoned up the carers they said "Oh she said she didn't need us anymore" so she just stopped them coming

This highlights the difficult situation between families and formal caring services and people with dementia when arranging formal care; should the formal carers listen to the care-recipient who claims they are not needed, or the family member who claims they are. B1 was frustrated that the care services had not communicated with her about the change, or give her the chance to explain that Case B had cognitive impairment. B1 was trying to get formal care services started up again when Case B had another hospital stay and subsequently moved into a care home.

Relocation

Case B began to recognise her need for institutionalisation because she usually felt disoriented in the mornings and because of her frequent falls. She wanted to feel safe. After another fall and hospitalisation, she was sent to another hospital for convalescence, and then relocated into her first care home. This was a residential-only home for which she was unsuitable. This was because Case B's GP was not fully aware of her needs:

B1: Our doctor at the time wasn't exactly hands-on he usually sent somebody else to see her and so when I said "Do you think she'll be ok for a residential home" he said "Oh yes" so I got her a place in a residential home

While there her behaviours included leaving taps running, wandering into other residents' rooms and:

B1: On one occasion she also tried to get out of the home during the night, set the alarm off and woke everybody up, so the care home were getting a bit fed up with her really

This disorientation was attributed by B1 to Case B's frequent hospital admissions prior to her relocation. Although she had been happy to relocate, whilst there her social skills became impaired and she did not mix with other residents as B1 had expected. She also began to suffer difficulty eating, but thought when she was moved to a different table to receive more carer support, that she had been put on 'the naughty table'. After another fall, she had a brain scan whilst in hospital and her dementia was diagnosed. At this point her first care home refused to have her back:

B1: They said "Oh she she's not coping you know she's got dementia we can't have her here she needs a nursing home"

B1 then had to find a suitable home for her mother. B1 had visited Care home #2 when searching for a placement for Case B previously but had chosen the first care home because Case B's friends had requested a location where they could easily visit her. However they never visited her in the first care home:

B1: I think they thought I was going to provide a taxi service for them I was going to drive them there every time or something

B1 then chose Care home #2 because it was a better location for her. A representative of Care home #2 visited Case B whilst she was in hospital to meet and assess her. She relocated to Care home #2 in February 2009. B1 was asked how she perceived Case B felt during this new move:

B1: I thought she'd be upset by it and I got the first place [Case B's first care home] to write a letter in large typing for her to look at so it was clear that it was their decision not mine to move her but she didn't really say much I was quite surprised she seemed to just take it for granted that she was here she was so disoriented by that time that she was sort of losing track of where she was

At the time of data collection, Case B had been in Care home #2 for a little more than four years.

Care home life

Case B is now bed-bound. More details of her limited mobility are in the Mobility section below. She is rarely able to verbally communicate her needs but sometimes rambles about the past or her interpretation of reality:

B1: Sometimes she'll chat but it usually doesn't make sense... she'll say she's been out to the shops or... things that happened before I was born you know [laughs] sometimes she'll mention someone I've never heard of and I have tried asking her a bit more about that person but she can't keep a conversation so I'm still none the wiser

She will more often be unresponsive to others:

K2B: You go in there and say what the weather's doing today and tell her if it's raining or you know sort of glazed over sometimes she will stare at one particular place on the ceiling... if I look there's nothing but I don't know she may be thinking something... she's well away

When she was more verbally communicative Case B would talk about going home and her parents coming to fetch her. She is unaware of her dementia and used to be fearful of being mentally ill. She often showed signs of anxiety such as calling out 'help', although she did not always know why she shouted 'help' just felt she needed it at that time. Reassurances from staff helped this most of the time. Although her verbal communication is impaired, before she was bed-bound she used to bang her head or bite her finger when agitated. There was a noticeable reduction in calling out by November 2012 due to illness. After that she was generally very calm but still reacts badly to loud noises. She used to love classical music and carers play her favourite music, such as Mozart and Bach pieces to soothe her. However B1 perceives that Case B is unaware of the radio:

B1: She's just lost interest... she just doesn't seem to remember it now if I say "Do you remember this piece" she doesn't

Similarly, she has now stopped watching her TV as she is now uninterested and does not seem to relate to her favourite nature programmes:

B1: I find some of the other residents are like it as well if there's three of them in a room they would just ignore each other... as though the other person wasn't there which is really sad... they seem to lose their social skills

Case B no longer participates in the social activities that Care home #2 provide but used to enjoy poetry readings on 'good days'. However she usually had difficulty understanding that by going to the lounge for an activity she wasn't leaving her home:

B1: If they said right "We'll take you down to do such-and-such an activity" she'd immediately want to change her clothes and do her make-up and of course they haven't got the time to do all of that with her... she didn't fit in so well

Although Case B no longer participates in structured social activities and is bed-bound in her room, B1 feels that Case B could have more human interaction:

B1: I think it would be nice if people came in and chatted to her a bit more than they do they always seem too rushed to do that

Before she was bed-bound Case B showed signs of depression; staff tried distraction techniques such as asking her to fold napkins or sort socks. Before she was bed-bound and uncommunicative, if she felt sleepy she would go to the sofa, pat it and ask to lie down on it for a while. She generally has a disturbed sleep pattern and can be confused on waking. She only sleeps for short periods of time.

Care home: medical and sensory conditions

In addition to her VaD, Case B's co-morbidities include: osteoporosis, migraines, occasional UTIs, constipation and epistaxis (nosebleeds). She has poor eyesight, but although she has an annual eye test the optician is unable to assess her properly because of her dementia. She is fully dependent on staff for administration of medications.

Care home: orientation

When she was mobile, Case B's poor short-term memory meant that she needed prompts and reminders to remain oriented. When she could speak she frequently asked where she was and the day and year. As soon as she left her bedroom she could not remember where she was and went

into other resident's rooms looking for her room. As she is now bed-bound and verbally uncommunicative, it is not known whether she has any delusions about her reality.

Care home: mobility

Although she was mobile when she relocated, Case B is now bed-bound. Prior to this she had poor mobility and slight pain on movement. She did not appear to be uncomfortable or frightened when she was hoisted for transfer activities. Sometimes she could walk with the help of two carers for short distances and used a walking frame. She suffered a number of falls, one of which resulted in a hospital visit for stitches in her forehead. The staff then had to keep a hat on her head to prevent her from scratching or picking at them. After this incident she always used a wheelchair as the carers did not want to risk her falling again. For a time, she could self-propel using her feet while in a wheelchair with a lap belt:

I: Do you know how she felt about that [the wheelchair and lap belt]?

B1: Well she did say once or twice she said oh I want a pair of scissors so I can cut the straps on this [laughs]... so she wasn't entirely happy about it no

Case B then began to suffer from a contracted right leg and very stiff left leg, so in November 2012 was assessed by the physiotherapist for a water-chair; however one could not be found to fit her body, according to K2B and as such she became bed-bound. She never attended the exercise sessions recommended and run by the care home physiotherapist.

Once bed-bound, Case B had a pressure-relieving air mattress on her bed to reduce her likelihood of developing skin sores. Although the mattress is audible it does not appear to bother Case B. Carers use her personal slide-sheet to turn Case B every four hours to help preserve her skin integrity. The hoist with sling is also used to lift Case B up for weighing. Carers are always careful to tell Case B what they are going to do before using the slide-sheet or hoist with her:

K2B: We always tell [Case B] what we're going to do yeah because you've got to and we say which way you're going to turn... because it must be quite frightening for two people to go in and just do something

Her bed has bed-rails with full-length bumpers which are removed during ADLs. Although her care record stated that she does not require a pressure alarm system because of her immobility, B1 claimed in the interview that she does. She did not, and does not, use her call bell. B1 attributed this not only to Case B not remembering to use it, but that formal carers left it out of her reach.

Care home: washing

Case B is washed in bed by two or three carers who use her slide-sheet to turn her. These bed baths occur daily and sometimes more frequently if necessary. She doesn't mind about the gender of carers during this task and is not aggressive during washing:

K2B: [Case B] always lets us do personal care and lets us wash her and she enjoys a hair wash

She is at very high risk of pressure sores on her sacrum due to being bed-bound, and at the back of her knees because contracted legs. Carers cream to her skin after washing to reduce this risk.

Care home: grooming

Although historically Case B was proud of her appearance and liked to wear make-up:

B1: She doesn't seem to want to comb her hair or do her make-up or anything she used to be very particular about doing her make-up when she first went into a home... but she isn't now no I don't think she can really

A carer cuts Case B's finger and toenails when necessary.

Care home: dressing

Case B receives full support to dress by the care home staff. She cannot choose her own clothes even when asked. She can sometimes obey commands such as 'can you hold your arm up' to make dressing her easier. She is dressed in day clothes although she never leaves her bed. She wears socks to stop her toenails scratching her between podiatrist visits. B1 has had some problems with Care home #2 in the past concerning dressing:

B1: I came in the other day and she was lying there she had a blouse on and she had a pad [for incontinence] which had come adrift no knickers no skirt and the bedding was all pulled back but she'd probably done it herself but you wonder how long it is since anybody's been to see what's going on... and one day she wasn't wearing any skirt I said "Why isn't she wearing any skirt" and she said "Oh I didn't finish dressing her because she was rather hot" so you never quite know how much actual care is going on

In the past, Case B was particular about her clothes and preferred beige and other neutral colours. B1 is also unhappy because although Case B only ever wore tights or stockings with a skirt, Care home #2 insisted that she had hold-ups or socks with trousers. This was likely to make dealing with continence issues easier, but is certainly still in B1's thoughts.

Care home: elimination

Case B is doubly incontinent. She used to become anxious and obsessed with potential continence accidents and would scream, self-harm or bang furniture when she needed to go to the toilet to gain staff attention. It is likely that Case B learned to behave in this way because of previous experience:

B1: The trouble was when she first came here... she started needing help going to the toilet and you can never find a helper... it was like a vicious circle they didn't come when she wanted them so the next time she'd ask them sooner and so on

Now she is bed-bound, Case B uses continence protection pads exclusively for her elimination needs, as her contracted leg means she cannot sit on a toilet or commode. The size and number of pads per day were determined after her fluid outputs were tracked and sent to an NHS Continence Nurse. Care home #2 receives the pads from the healthcare system. Each pad is supposed to last for four hours. Case B now does not appear to be distressed about her incontinence or use of the pads:

K2B: She never gets annoyed when we've had to change them or anything like that you know... maybe sometimes she says thank you... I don't know whether you ever get used to it someone comes and does... personal care and whatever but... she never gets angry

She takes a Laxide drink to help her open her bowels.

Care home: eating

The stand-aid hoist is used to lift Case B up and weigh her. Her weight has 'yo-yoed' over time while at Care home #2 with a BMI ranging between 19kg/m² to 23.9kg/m² (both still in normal weight range).

Case B has pureed food and thickened drinks as she has swallowing issues related to reflux (not related to the swallowing mechanism) for which she was treated in the past. A SALT assessment in May 2011 showed she had reduced oro-motor musculature and a slight tremor in her tongue. Her portions are now small to help reduce clear phlegm that was coming up after food. Her reflux was managed by suctioning around her mouth (not behind the throat). Her food is given to her by carers using a spoon. She cannot use a spoon herself but can hold and use a two-handled plastic cup with a sip-top adaptation as long as a carer is holding one of the handles:

K2B: She will hold one we will hold the other she's not got the co-ordination... because I have tried she held it in her hand and she went [mimes spilling on herself] and it never goes in her mouth it always goes somewhere different so you do have to help her

When asked if Case B would recognise she was thirsty and reach for a drink next to her:

B1: They don't usually leave it within reach... she has a fluid balance chart and I'm surprised how little she has to drink actually if you add up what she's had in a day

B1 sometimes gives Case B drinks but perceives that the staff do not wake Case B up for drinks during the day if she is asleep. The thickener does not have a negative impact on urine output. The care home staff are able to interpret Case B's eating and drinking behaviour:

K2B: Sometimes we have to say "Oh [Case B] could you open your mouth" but then after a while she would just do it automatically you know for a drink but if she doesn't want to drink she will bite on the beaker she'll just bite it... she'll just take a little bit off the tip of the spoon when she's had enough

Although Case B has physical problems swallowing food as described above, K2B believes that Case B's eating difficulties are also related to cognitive impairment:

K2B: I couldn't be a hundred per-cent but I think it was her memory that you know as you watched her as time went by you could see just little things slipping

Previously when she was able to feed herself she did so with the help of a plate guard and special plate-bottom to prevent it from moving on the table. She used normal cutlery.

Care home: family visits

On her visits B1 sometimes combs Case B's hair 'if it looks a bit messy', or tidies her bed clothes if necessary. She does not need to meet Case B's elimination needs because of her continence pads. She would be scared to dress Case B because she is very frail, but has given her perfume to try to relax her or evoke memories. She sometimes gives Case B drinks; the thickener is always kept in her room.

Care home: end of life plan

A DNR Form was completed in January 2013. Case B has been assessed as unable to make her own arrangements regarding the end of her life.

Case C Stage Two case study

Case C is a male in his mid-80s. He has AD which was diagnosed 12 years ago.

Cognition

Case C developed dementia after ten years of retirement. As there is no history of dementia in Case C's family, C1 and Case C's doctor believe that his dementia was caused, or hastened, by the anesthetic from multiple operations he had for gall stones and hernias. One of the first signs was his disorientation:

C1: When he was in hospital he couldn't remember where his bed was getting back from the loos...then whenever we went to hotels he couldn't remember the way back to the dining rooms and even in the room he couldn't find the en-suite toilet facilities

There were no other signs at that time such as a lack of concentration or poor hand-eye co-ordination. C1 cannot remember whether the hospital staff gave Case C an MRI scan or suggested they visited a memory clinic during the time of diagnosis. He then had six-monthly reviews by an Older People's Mental Health team to track the progression of his dementia.

In March 2013, while in Care home #2, Case C had a marked deterioration in both cognitive and physical function that occurred over a one-week period. Now he no longer responds to commands. He cannot express his needs through verbal communication or understand others, but may use non-verbal communication. His cognitive impairment leaves him vulnerable.

Family history

It was Case C and C1's 54th wedding anniversary on the date of C1's interview. They have one son and one daughter. However their son died when 18 years old. Their daughter has four children. C1 worked as a teacher in secondary schools. Case C has a PhD in physics and worked as a researcher and finance manager.

Community life

Case C lived at home with his wife, 'C1', in a bungalow in the same town where Care home #2 is located. They moved to the bungalow in approximately 2006 when his AD 'started to kick in'. Case C's mobility problems will be detailed further below, but eventually C1 could not go anywhere with Case C:

C1: In the end I couldn't get him out of the car but we still had lots of friends fortunately so he had lots of people visiting him [here at home]... but in the end your social life and his is very much diminished because you can't get him anywhere and some people are very uncomfortable with somebody who has Alzheimer's

As such, their social connections began to suffer because of Case C's condition.

At home: medical and sensory conditions

Whilst living in the community, Case C had operations to remove an inguinal hernia and a total cholecystectomy to remove his gall bladder. He had Galantamine tablets for AD, 12mg in the morning and 12mg in the evening, since he was diagnosed:

C1: When he was prescribed it at first the consultant said "Well we don't really know about this but it might kill him" and I said "Well he's gonna die anyway so let's go for it" so we did

and he's been on that for over ten years first he was on a lower dose and then it's increased and then twenty-four milligrams is the highest

At home: orientation

At home Case C was generally oriented to his surroundings. After returning from hospital they turned the dining room into his bedroom to accommodate the hospital bed. This was opposite the bathroom and he did not require room signs:

C1: He seemed to grasp that until he couldn't literally get himself there... it's all on one level and he was only really in the lounge the bedroom the bathroom and in the end he wasn't in the kitchen even so just three rooms he didn't have any problem but if the house had been larger he might have done

The bungalow environment was therefore suitable for his cognitive and physical functioning regarding orientation until his mobility began to impair his ability to reach the room.

At home: mobility

Although he used a walking frame after a fall in September 2001, Case C was independently mobile. However over time his decreasing agility was a significant problem. He began to lose the use of his legs and required a wheelchair. C1 had a ramp installed at the back of the house to enable Case C to enjoy the garden but he rarely used it. C1 was not comfortable with the idea of having a hoist in her house but this was related to her mistrust of formal carers turning up on time. This is discussed further in the Informal and Formal Carer Assistance section below. The county social services loaned a hospital bed for Case C on request; C1 found this the most useful technology they had.

At home: washing

C1 had the bath in the bathroom removed at her own expense; she was unaware whether there could be any financial aid to her:

C1: I didn't find any help was available to me financially 'til it was too late nobody told me that you could get grants for this and grants for that... at that time nobody told you anything now I know I could have had a Carer's Allowance or Attendance Allowance... I believe now they're much better at telling people these things I hope they are

A stand-up shower replaced the bath because it was easier for Case C to use this. She also bought a stool for him to sit in the shower, and hand grips to enable his balance. A seat with handgrips for the washbasin was provided by the county social services. Case C responded well to all of these aids.

At home: grooming

Case C could conduct his own oral-care while he lived at home. Over time he could no longer shave. This was because he could not remember what tasks to perform rather than, for example, because of physical difficulties holding a razor. Formal carers performed this activity for him.

At home: dressing

Case C's ability to dress gradually deteriorated over time because of his cognition:

C1: So I had to put out the clothes he was gonna wear in the morning he couldn't select them

I: I'd just like to clarify that was because he couldn't remember what to do rather than physical?

C1: Yes

At home: elimination

Case C was incontinent. C1 bought bed-sheet protection and was provided pads for his underwear by the NHS Continence Nurse. However C1 was not happy with these pads:

C1: They provided ones which were like baby's Velcro nappies which are not really suitable for people with Alzheimer's I couldn't manage them he couldn't manage them

Then C1's cousin recommended the pull-on pads she had used for her husband with Parkinson's disease. C1 found these to be extremely helpful because Case C could use them himself. However she had to be persistent to obtain these from the Continence Nurse:

C1: I said "Look my cousin sent me down a packet of these"... she said "Oh no we can't provide those... it's cost"... well she sent me various variations of the other type all of which were useless I said "Look you're sending me boxes of these I'm not using them you can't take them back I'm giving them to the District Nurse to use for when she goes round" and because I'm very persistent I think [laughs] I eventually got them

In her bathroom modification, the county social services also provided a raised toilet seat and hand grips for around the toilet. They did not want the toilet seat to be returned after Case C relocated to Care home #2.

At home: eating

Case C could feed himself when he lived at home. C1 prepared all meals.

At home: informal and formal carer assistance

C1 initially cared for her husband herself, but struggled with this because she is petite and Case C is six feet tall. To provide some respite she paid £60 for a private sitter once a week on Tuesdays and £10 to a charity for a few hours respite care on Thursdays. However after breaking her arm, health professionals sent in a rapid response team to temporarily assist the couple. C1 then contacted a formal carer company to assist Case C to get him up in the morning, wash, shave and dress him. Carers also came to put him to bed in the evening. Eventually however even the formal carers could not manage Case C due to his increased inability to stand up:

I: Why did that occur was it a cognitive ability to understand to get up or was it physical in terms of muscle wastage or...

C1: No no he had the doctors he had tests to see if it was circulation to see if it was loss of muscle power no it was simply the brain didn't tell his legs to move

C1 was reluctant to have a hoist because she felt she could not trust the formal carers to both turn up at the same time and was suspicious of the quality of their care:

C1: The problem with the care providers is that at the moment anybody can set up a facility and say they're care providers I'm very dubious about the training that some of them had... in the end I would have needed two people to come probably twice or three times a day the problem was they didn't turn up at the same time sometimes they don't turn up at all it was just getting too stressful

She felt that the problems she had with formal carers were a result of their being under-paid, over-worked and poorly organised. She did feel however that they were caring individuals:

C1: They were really caring people lovely people very caring towards [Case C] and me... because you wouldn't do it if you didn't care for the people because you certainly not paid [laughs] no money to do it you're certainly not

Furthermore, even if the carers turned up at the allotted times, if Case C had a continence accident he would have to wait to be changed because C1 could not do this.

Relocation

Case C lived at home for 10 years after his dementia diagnosis. Due to his increased difficulties with mobility and falls history the county council conducted a comprehensive health and social care individual needs assessment in August 2012. The outcome recommended that he relocate to a care home. Case C expressed his wish to stay at home but agreed that he didn't want to put his wife in a situation she was struggling with. C1 did not want Case C to relocate either but due to: the lack of reliability of the formal carers, their inability to move him without a hoist and her daughter's encouragement, she made the decision. C1 also took advice from the care manager assigned to her by the social services:

C1: She said "I think you should look at some [care homes] because if he deteriorates very quickly and gets into hospital they will then say to you after a few days "Where's he going to go now" and you'll have to make a quick decision and it might be them pushing you into somewhere that you don't want to go rather than if you choose yourself" so she spoke to me about it at length

C1 and her daughter visited all the care homes in the local area. She decided on Care home #2 because she knew a staff member who worked there and recommended it as 'homely and friendly'. She was also put off by other care homes which locked up the residents with dementia in specific wards; in Care home #2 residents are able to walk throughout all areas. Case C initially visited Care home #2 for one week respite care as C1 was still unsure about a relocation:

K3C: Once he was here she realised... he needed more care than what she could give him

C1: Because they were so lovely with him much to my daughter's and my surprise he seemed to settle in really quickly and so I said to them there perhaps he could stay another week and just see what happened and then I still wanted to bring him home but then I thought I'm just gonna confuse [Case C] if I bring him home and then take him back again and then I decided that if he went I wouldn't ever bring him back home again because I just thought it would be too upsetting... it's a very very difficult decision to make

Case C then never left Care home #2. C1 was still unsure that she had made the right decision at that point, but now feels it was.

Care home life

Now, Case C requires a high level of support to fulfil his social needs. He used to take part in social activities such as quizzes, games poetry and reminiscence activities but no longer does. The care home staff are advised that he should not watch violent films but enjoys rugby, music, history, science and wildlife programmes:

C1: He can't tell you about them but you know by his face that he's absorbed in them whereas if you put on EastEnders he's not interested... he never was interested in those sort of things with care homes it's some of them think one programme suits everybody and they don't

He appears settled both mentally and emotionally. He exhibits calm behaviour. He rarely leaves Care home #2 on day trips because he suffers from travel sickness. However the staff have recently obtained tablets from his doctor to try with him, first on a short trip and then on an upcoming male residents' day out:

K3C: He likes the garden... and he loves trains as well so I think in September time there's an exhibition thing going on so that's why we're going just take him for the cup of tea first see how he gets on in a minibus

He spends a lot of time in his room but is not depressed. He does not require assistance to sleep. When asleep, his door is closed but he is checked hourly by night staff.

Care home: medical and sensory conditions

Case C changed while at Care home #2 from chewable tablets for his AD to Galantamine Syrup. This was because he became unable to chew his tablet and spat it out frequently. However his doctor has now stopped the AD medication:

C1: Now they've just said that it's not doing him any good so they're going to take him off it but I think that kept him at home for at least another six or seven years... this doctor said "It's not having any effect"

I: Ok how do they know if it's not having an effect?

C1: Well this is it how do they know don't know I suppose now it's got to the stage where nothing makes any difference

In addition to AD he experienced a chest infection throughout November and December 2012. In June 2013 he collapsed; this was attributed to temporal lobe atrophy consistent with a symptomatic postural drop (sudden drop in blood pressure) and AD:

K3C: Because of his type of dementia he's got each time he gets like any kind of infection it kind of knocks him down a little bit further

He also has hearing weakness. He is fully dependent on staff in Care home #2 for administration of medications, as is the home's procedure.

Care home: orientation

Case C has marked disorientation of time, person or place and fails to recognise and appropriately use everyday items. He cannot locate his bedroom.

Care home: mobility

Case C is a High Falls risk as he can forget that he cannot walk on his own. He can move his arms but his other mobility is restricted. He must have two carers who use a hoist and handling belt for all of his transferring activities. However hoisting can be a problem because of the size of his bedroom:

K3C: The amount of stuff he's got in there you can't it's like a jigsaw you have to jiggle it about... once he got over the chest infection we did try and stand him again but he just didn't have the strength to do it so you know obviously his safety comes first

He used to use a walking frame plus two carers to walk but now has a wheelchair. He had a normal wheelchair but then became too high a risk to use it because of his balance. The care home physiotherapist then assessed him for a water-chair:

K3C: It reclines back and his legs tip up and everything... he was confined to his room for those two months because he was too high a risk in the normal chair... he's much happier now that he can go up and out round the garden

C1 paid for the water-chair. He can reposition himself when sitting in a chair but may need prompting to push himself back. He has no pain at movement or at rest.

Two carers must use a slide-sheet to reposition him while in bed. The height of his bed can be adjusted as appropriate for the carer. He has bed-rails but not bumpers on these as he doesn't try to get out of bed on his own. He does not have soft cushioning on the floor or a pressure alarm system.

Care home: washing

Case C requires care staff to assist with bathing and washing. Case C does not like to be washed by others but will allow the carers to do it. Case C is washed by male and female staff and there are no concerns registered by his family about this. Although the care record stated that he should have two staff for this:

K3C: He's actually better with one carer in there because if you've got two in there he's quite naughty he gets a bit lazy and [when] you're trying to say to him "Roll over" he pushes against you but if you're on your own and say "Ok I need you to help me" he will but once he sees two of you he thinks "Hmm I don't need to do anything"

Case C can be prompted to perform movements such as raising his arm when required, if he is in the mood to. He has daily washes in bed and a full bath twice a week. Carers use the hoist and sling to lift him in and out of the bath. He cannot soap himself because of his cognitive impairment:

K3C: He doesn't know what to do I mean if you put a flannel into his hand he doesn't know even if you put it to his face he can't understand

C1 is unhappy that Case C has a bath and would prefer for him to have a shower. However there are no showers in Care home #2 so she is currently trying to get them installed.

Waterlow Pressure Risk Assessments have shown that Case C may be At Risk of pressure sores. Care home staff cream his head, legs and arms to preserve his skin integrity and manage eczema.

Care home: grooming

Although Case C could brush his teeth when he first relocated to Care home #2, carers must now clean his remaining teeth:

K3C: He doesn't like it you know he's moving his head round all the time while you're doing it

They also remove his dentures, soak them overnight and insert them in the morning. He receives shaves with an electric razor or sometimes has a wet shave:

K3C: He hates being shaved his wife did buy him an electric shaver but he hates that as well so we have gone back to the wet shave... he hates it but [if] there's a male carer on I do try and get them to shave him

He is now unable to comb his hair, even with prompting, but likes to have his hair combed or brushed by others. A podiatrist visits to take care of his feet and toenails.

Care home: dressing

Care home staff provide complete assistance to dress Case C. He can no longer choose his clothes but staff do try to involve him in the activity:

K3C: If you pick them out he just kind of looks as if to say "What are you on about" so I say "Oh well this one's nice today it's gonna be nice and hot"

He has no ability to fasten clothes. He used to have buttoned shirts and smart trousers with zips but when he began to be hoisted it was difficult for carers to negotiate removing his clothes for toileting. He now wears elasticated trousers to make toileting easier. He cannot regulate his body temperature so requires support for this.

Care home: elimination

When he first arrived at Care home #2, Case C was wearing the aforementioned pull-up style of continence pants:

K3C: Well when he first came in he had what they call pull-ups 'cause apparently that's what he had at home he could do that himself pull them up and down but when you're in a nursing home the PCT [Primary Care Trust] they don't authorise those kind of pads so now he has underwear on and then a pad that goes in between

Although C1 was not happy that he was going back to pads, she saw it as 'their [staff's] problem'. Case C is also routinely hoisted over a commode in the morning, afternoon and evening. This elimination routine is beneficial to him, however as Case C cannot alert others if he needs the bathroom, accidents do sometimes occur. He cannot wipe himself after evacuating his bowels. He sometimes takes Movicol (a laxative), although not daily as he generally goes to the toilet well.

Care home: eating

Case C is of medium build. His weight has slowly reduced since his relocation and is now 74kg at the time of data collection. His BMI is 22kg/m² (normal weight). After a chest infection, Case C began to forget how to swallow so either held food in his mouth or kept chewing and eventually spat the food out. He has also been known to sit and look at his food, particularly if he is unwell. As meals took a long time he would lose interest:

K3C: He's quite a pickle actually because he likes what he likes his wife brings him in chocolates and sweets and biscuits and you put them in front of him and he eats them on his own no problem but you put anything normal food for you know like dinner-wise he just chews and chews and chews he won't swallow... but breakfast he can eat on his own

By recommendation of a SALT assessment, a diet of normal consistency was stopped in February 2013 and a soft diet started. He requires one carer to provide physical assistance for food and fluids. He cannot use a modified plate or cutlery because he cannot understand how to use them. He can feed himself if the carer puts the food on the spoon and then hands it to him:

C1: It's the brain not telling his hand to do it [hold the spoon] and it's the brain not telling him to chew nothing wrong with his arms or his hands he has nothing else wrong with him except Alzheimer's so it's the brain that's not telling his limbs to work

He also has thickening fluid put into his drinks as he began to find it difficult to swallow liquids. He has a beaker that has two handles each side without a lid:

K3C: But again you can't leave him unsupervised because he might nod off and then can spill the drinks or he just lets go of the beaker so you have to be there with him

C1 selects his food from the menus each Monday for the week ahead.

Care home: family visits

C1 visits Case C regularly and is very involved in his care. The only ADL tasks she performs with Case C is feeding him at supper time, occasionally combing his hair or cutting his fingernails. Family members sometimes take him into the garden on their visits.

Care home: end of life plan

Case C has a DNR Form and living will related to advanced directives. These include notes made in March 2013 to refuse all medical treatment especially that which aims to prolong or artificially sustain his life. He consented only to medical treatment that aimed to help make him comfortable, and so far as possible, free from pain. He has been assessed as unable to make his own arrangements regarding the end of his life.

Case D Stage Two case study

Case D is a female in her very late 90s. She has VaD which was diagnosed five years ago.

Cognition

Case D's diagnosis of dementia was only disclosed to D1 during a hospital visit for a fall:

D1: It was only somebody in another hospital visit who said "You know your mum's got VaD"... I then looked that up and thought yeah that's what she's got... it's not Alzheimer's you know she doesn't have memories way back or things like that it's just simply she doesn't remember everything it's been a very gradual process

Case D's cognition then deteriorated rapidly during an elongated hospital stay after another fall. A Clostridium difficile outbreak prevented D1 from visiting Case D for four days:

D1: They still weren't really taking visitors but they said your mum is struggling maybe you should come in... she was like a different person

D1 extrapolates that Case D's cognitive deterioration was caused by malnutrition due to the hospital staff neglecting to ensure that she ate the food that was put in front of her. Her capacity level leaves her vulnerable and she has been assessed as unable to make informed decisions regarding her care. D1 has LPA but Case D is encouraged to make uncomplicated decisions pertaining to her care. She has no insight into her condition.

Now Case D can sometimes answer 'yes' or 'no' although at other times has incoherent and irrelevant speech. She has a tendency to talk to herself for long periods, but finds comfort in doing so and does not want to be disturbed otherwise will become irritated.

D1: There are times when I'll say to her "I'm gonna have to go now" and suddenly that cuts through and she'll say something like "Well take care mind how you go" as clear as can be... and then there are other times when she uses phrases [like] "That's all there is"... phrases that we use in everyday conversation without really thinking about the meaning [but] I don't think she really knows what it is she just comes out with them

K4D: She recognises what you're saying but she can't react to your questioning we ask her stuff and she might just say "No" or "Yes" but she doesn't know what she's answering yes or no to

Although her use of such phrases may be in appropriate positions in conversation, both D1 and K4D feel that Case D is not truly able to communicate or participate in a conversation any longer. As she has difficulty expressing herself she will bang on the table if experiencing pain. She is sometimes unsettled and both physically and verbally abusive. She is bewildered by everyday events and often shows signs of anxiety and requires constant reassurance. She also shows signs of depression; she is withdrawn, cries and refuses to eat.

Family history

Case D was born in a different area of the country to where she lives now. She has skills in dress designing and making. She was married in the 1940s but is now widowed. Case D has one child, daughter D1, and they enjoy a close relationship. She also has two granddaughters and a grandson. She enjoys flower-arranging and owning dogs.

Community life

Case D cared for her husband for eight years after he had a stroke; originally he had only physical difficulties but after further strokes and TIAs became unable to communicate verbally and was cognitively impaired. He became bedridden and could only eat pureed food. At that time Case D and her husband lived approximately an hour's drive from their daughter so Case D conducted many caring activities alone. She refused for her husband to enter a care home and hated his going into respite when she had knee and hip operations, so the house was converted appropriately; an OT assessed the house and the local council granted funds to mount hand-rails throughout the house, convert the dining-room into a bedroom and install a downstairs bathroom with a shower unit. Case D also slept downstairs so that she could hear her husband in the night. They received formal carers in the house twice each day to perform ADLs with him. These carers were arranged through their GP who then contacted social services. They also used some mobility-related technology, first a manual and later an electronic hoist. Although D1 noted that social care services and formal carer services were generally easy to work and communicate with regarding her father and later her mother, they did have to 'push' to access the electronic hoist for her father:

D1: My mother spent a lot of phone calls on [accessing a hoist]... so she really pushed

I: It's interesting that you're using words like push

D1: Yes but again you know I'm a bit like that but also my mother was very able at that point to make phone calls and be pushy... it was essential to keep my father there which [and] presumably would have saved them money in the long run

After her husband's death Case D decided to remain in her home rather than move to be closer to her daughter. She had a network of friends and neighbours who she wanted to remain near. Overall however their experience of caring gave Case D and D1 insight into potential difficulties and impacted upon their decisions in the future when Case D became physically and cognitively impaired.

At home: medical and sensory conditions

Case D at first experienced many conditions including cardiovascular disease, hypertension and arthritis. Her macular degeneration meant that she had to give up driving; D1 feels that Case D always secretly regretted this because it reduced her ability to perform IADLs such as shopping.

She also had two knee operations and a right hip replacement. Injuries from her frequent falls including bruising and wrist fractures, however D1 suspects that some falls were the result not of reduced mobility or sight but due to TIAs and poor balance because of, at that point undiagnosed, VaD. K4D indicated during a discussion on Case D's eating ability that she has had a stroke at some point in the past.

At home: orientation

At home Case D recognised that she was a little disoriented as she kept forgetting how to turn the television off. When confused she would telephone her neighbours and ask them for help. As another main issue was Case D's failing sight, D1 perceived that room signs in her house would not have helped with Case D's disorientation unless they were in large font.

She then fell and broke her wrist while in hospital recuperating from a different fall. That according to D1 'really was the end' for Case D's ability to live; she was taken home for an assessment to see if

she could live alone there but was muddled where items were when observed trying to make a cup of tea. This is further described in the 'Relocation' section below. Later she also could not understand why she could not live at home.

At home: mobility

Although Case D's mobility was well enough after her knee and hip operations, she began to become more physically impaired in the time after her husband's death. D1 insisted that she did not use the stairs in her house and that she remained living in the downstairs area as she had when caring for her husband. Due to a history of falls Case D had a walking frame after turning 90 years of age, this she used sporadically so D1 encouraged her to use a food trolley on wheels when indoors. Yet she did not always use the trolley either; this was not attributed by D1 to Case D's thinking it was ugly or stigma-inducing:

D1: She would get up with her teacup in her hand and she would walk she'd just forget that she was meant to put it on there and then push it... but you can't make somebody do that [laughs] you know

She also had a telecare alarm to alert others in emergencies which she always remembered to use:

D1: This was the awful thing because she did start to have falls and so she was really meticulous about wearing this button but then the last fall at home the telephone had gone wrong... she was on the floor the whole night because the buzzer didn't work

The morning after Case D fell and her telecare alarm failed, a formal carer found her and accompanied her to hospital.

At home: washing

The ground-floor bathroom, installed for Case D's husband in the space previously occupied by a larder and downstairs toilet, included: hand-rails, a flexible shower mechanism and easy-use taps. It was in a wet-room style so that the large space enabled him to be wheeled in on a shower seat and remain seated during showers. Without the downstairs bathroom D1 believes that Case D may have had to leave her house sooner than she did. Over time Case D had formal carers to help her shower in the ground-floor bathroom regularly. Once a month she was helped up the stairs to the first-floor bathroom to have a full bath.

At home: grooming

No data on Case D's ability to perform grooming activities while she lived at home were extracted. She had formal carers enter her house three times per week for housework who also checked that she was clean and well.

At home: dressing

Case D had no difficulty dressing when she lived at home.

At home: elimination

Case D did not have difficulty with elimination or continence when she lived at home. However on her daughter's advice she only used the ground-floor adapted bathroom which had hand-rails to help her impaired mobility and make toileting activities easier.

At home: eating

Case D was able to prepare meals and intake food when she lived at home. She did not require adapted eating technology and was not at risk of malnutrition.

At home: informal and formal carer assistance

Neighbours acted as informal carers for Case D in times of emergency. She also had formal carers enter her house three times per week to perform some housework tasks, do her food shopping and ensure that Case D was clean and dressed. They did not need to prepare food for her. These were from the same formal caring company that Case D's husband had to help with ADLs.

Relocation

The initial decision for Case D to enter a full-time formal caring situation was as a result of an assessment at her house. Social care professionals accompanied Case D home from hospital and asked her to make a cup of tea. She was unable to complete the task because she could not find all the items she needed and remember the correct steps. D1 was present at the observation but not allowed to speak or participate in any way; she felt that because Case D was not given time to reorient herself back into her home after an extended period away that she was 'set up to fail'. The professionals advised that Case D was unable to live alone and Case D agreed that she would relocate to a care home near her daughter:

I: Was that quite surprising knowing her feelings about [institutionalisation] when she was caring for her husband?

D1: Yes but my mother is an immensely practical person and she recognised that she was having difficulties [but] I think as soon as we eventually found somewhere for her she regretted that decision because she felt she could have been independent

D1 could not bring her mother to live with her because she provides care for her daughter who has Myalgic Encephalomyelitis. Case D had to remain in hospital while her daughter found her a care home so D1 felt pressurised to find somewhere appropriate quickly:

D1: We spent a long time searching for [a care home] but always conscious of the fact that whilst we were looking my mother was deteriorating in a hospital

With a list of care homes from the county council, D1 selected a local family-run residential home. However Case D was not stimulated there; she did not socialise with the other residents well or settle in to care home life:

D1: She changed when her hearing was getting poor her sight was getting very poor and the two things meant that she just didn't communicate very well with the other residents... also she was used to being with people who were younger... and she would say "That old woman over there" she never saw herself as old

She also suffered with constipation which caused a high temperature:

D1: They got worried and they didn't have the medical qualifications so they decided to send her to hospital I hadn't known that if you are very constipated it can actually affect your cognitive functions as well

As was described in the previous 'Cognition' section the hospital staff did not ensure that Case D ate so she became malnourished and further cognitively impaired. She also became extremely physically impaired as in her five days there she was never assisted out of bed to walk:

D1: So of course she lost her ability to stand and that was crucial to the care home taking her back because if she couldn't stand they felt they hadn't got the facilities to look after her

Although the care home eventually accepted Case D back they refused to accept her after another fall and hospital stay. She was at her first care home for two years and relocated to Care home #2 in October 2008. This home was chosen as it was the first of D1's two preferred care homes to have an opening to take Case D. A particular criterion was for Case D to have a ground-floor bedroom to enable her granddaughter to visit her.

Care home life

Case D's keyworker K4D noted that when she first entered Care home #2 Case D was lively and chatty; she now rarely talks. She requires a high level of support to take part in activity programmes and to fulfil her social needs. Case D's failing sight has resulted in a reduced ability to participate in the art and craft activities she used to enjoy. Her impaired cognition also affects her concentration on television or radio programmes and ability to operate these devices correctly. She is no longer interested in her classical music cassette tapes. She attends the church service at the care home on Thursdays or the priest visits her if she is unable to attend that week.

She frequently has trouble sleeping and requires support from two staff with night care. She used to bang on the table in front of her if she wanted to go to bed but now does not.

Care home: medical and sensory conditions

In addition to her VaD, Case D suffers osteoarthritis and chest infections. She had pneumonia in August 2011. She has monthly visits from her GP because of hypertension. She has a history of stage 3 chronic kidney disease. She is known for being reluctant to take medication. She wears spectacles and two hearing aids.

Care home: orientation

Case D now experiences severe disorientation. She could not find her way around Care home #2. She rarely indicates that she understands what is going on around her. However she will sometimes become agitated when in the sling being hoisted during transfer activities because she does not understand what is happening:

K4D: We'll just lower her straight on the bed and leave her on the bed for a little while rather than leaving her struggling in the air

Case D's cognitive impairment hinders her ability to understand what the hoist is and that she is safe while in it.

Care home: mobility

Case D's mobility is very poor and she now cannot weight-bear. When she walked she had a history of falls because she was reluctant to use her walking frame:

D1: But you can't make somebody do that you know I mean when she got into [her first] care home they tabulated all her falls and she had over a hundred in about three months it was ridiculous

Both her knees are now contracted which leaves her chair-bound. She has her own pressure-relieving water-chair with built-up sides and a lap-belt to prevent her from falling out as she tends to lean to the right. She once fell out of the chair when staff forgot to fasten the belt and she tried to stand. At first she shared a water-chair; she had it in the afternoon after another resident used it in the morning. D1 then considered buying Case D her own water-chair but since the other resident died Case D has full use of the chair. Staff must use a stretcher with her if she is required to leave Care home #2 for appointments.

Case D has an electric bed to enable her to be sat up. Her bed has an air mattress, bed-rails and bumpers as she is at risk of falling out:

D1: She's not mobile but she's quite strong still and I've seen her kicking I feel she could probably roll out of bed not intentionally but I'm glad to know that those are there

A slide-sheet is used to reposition her while in bed. She does not use the call-bell in her room because she cannot remember how to use it.

Care home: washing

By the end of her time at her first care home, Case D could be encouraged and prompted to wash herself. Now she is washed by carers. She has a weekly bath using a mechanical seat and sling to lower her in and lift her out safely. Other days she receives bed baths from two carers during which she is repositioned using a slide-sheet. She doesn't mind having male carers but can sometimes be physically aggressive or reluctant when receiving care with intimate activities. However the care record noted that she is unhappy in the bath but K4D stated that she is happy in it. A Waterlow score demonstrates that she has Very High Risk of pressure ulcers. She has a dry scalp and skin and is prone to skin-tears, so is creamed regularly.

Care home: grooming

As with washing, when residing in her first care home Case D was prompted to perform grooming activities such as brushing her teeth and hair herself. She declined over time and now cannot perform any such activities; not only due to her cognitive inability to perceive prompts and instructions but because she physically cannot balance while sitting:

K4D: She can't do anything anymore... not for herself

Staff brush her teeth but find this difficult as she can become non-compliant and unhappy. A manicurist sometimes takes care of her nails or staff cut them.

Care home: dressing

When she first moved to Care home #2 Case D could dress herself but found it physically difficult to perform some activities such as bending down to put stockings on. Now she requires total support to get dressed, although sometimes may be able to say what she wants to wear if given two choices:

K4D: We ask her and sometimes she just says yes to what whatever you hold up... we tend to put her in what she used to like

She always prefers a blouse and skirt with a cardigan or full dresses, and beaded necklaces:

K4D: She likes red beads with a blue dress or pink ones with the green [dress]... I would have it the other way around but [Case D] doesn't she's always had it that way round but then she likes vibrant colours

She does not indicate that she is aware of her body temperature so staff must manage this for her.

Care home: elimination

Case D is fully dependent for her elimination needs as she is incontinent of urine and leaks faeces. She cannot alert staff when she needs to use the toilet. When she has soiled herself she scratches and digs down below so staff need to watch for this; her pad is checked every two hours when she is in bed. She uses medium continence pads for day and large pads at night. She is prone to both UTIs and constipation and has laxatives to prevent this.

Care home: eating

Case D is 1.43m tall and at her last weigh-in was 30.4kg. She is classed as underweight according to her BMI score. She may refuse meals due to drowsiness which leaves her vulnerable to dehydration and malnutrition:

D1: In extreme situations she'll spit it out [and say] "No" her language can be very clear on that

She went on NHS Continuing Care to monitor her weight and now has Ensure drink and Forticreme vitamin supplements to her diet. She requires full support to eat, drink and choose food but may be able to say 'yes' and 'no' when given options. She usually eats her meals in the lounge with the other residents but sometimes prefers to eat in bed. She tends to swallow food very quickly without chewing so requires monitoring to prevent choking; and has a pureed diet. This however had been a source of conflict between the family and the care home:

D1: I was a little bit annoyed here they very quickly put her onto a pureed diet but I think it was probably she would take so long to choose something it was probably not practical... I asked them not to they went back to chopping it up but then very quickly went to pureed again

Whilst D1 thought that Case D's pureed diet was due to taking too long to choose, K4D stated that it was because Case D has swallowing difficulties. K4D also explained how they managed D1's resistance to the pureed diet:

K4D: We discussed with the family [D1 said] "Well I don't think I really agree with that" we'd let it go for another month or so and then we'd say "I'm sorry but she really needs this" and then we discuss that

Staff should encourage her to eat snacks between meals, particularly pureed cakes:

D1: She seems to have got a very sweet taste now which she didn't used to have

She takes the pureed food from a spoon held by carers. She used to use an adapted spoon and a plate with rimmed edge. The adapted cutlery and plate were supplied by Care home #2 after staff noticed that she was having difficulty with grip strength and only noticed food on one side of the plate. They then trialled the eating AT with her:

K4D: But then that [action] slowly diminished more and more so it's gone now

Her drinks are not thickened despite K4D's indication that Case D has swallowing difficulty. She can no longer grip a cup or beaker so staff hold a cup to her mouth whereby she can suck the liquid from a sip-top.

Care home: family visits

D1 visits Case D once a week, typically on a Sunday as she works full-time. She sometimes assists Case D with feeding and does this because of Case D's continued weight loss. Case D eats well for her daughter and sometimes noticeably better than for staff:

K4D: She actually eats better for her than she does us some days because she's constantly talking to her about what [Case D] remembers whereas we wouldn't be able to speak so much

D1 also helps because Case D commonly falls asleep during mealtimes and D1 is afraid that the care home staff then remove her food. Therefore when she visits she can guard the food until her mother wakes up and eats again. D1 also likes doing this activity with her mother because Case D is no longer able to chat and hold a conversation. The care home staff are happy for D1 to feed her mother. Indeed D1 has a good relationship with the formal carers and is pleased that many are long-term employees to enable trust and friendship to develop with the residents and families alike:

D1: Some homes have such a quick turnover they can't form relationships at all

D1 also noted a time in the past where staff had to rotate between the different wings of the home every four weeks. Although she theorised that the scheme was in place to prevent staff becoming emotionally attached to residents, D1 disapproved of it as she perceived it to be upsetting for the cognitively-aware residents who had formed bonds with staff. She was thankful that Case D was already cognitively impaired enough not to have noticed when this happened but she did not consider the impact to her mother's orientation. Eventually the scheme was abolished and now staff typically remain in the same areas:

D1: I think consistency is good and I'm sure they're professional enough to keep their distance I know that they're dealing with people who might die at any time which makes their job hard but I'm sure they can deal with that and still sort of recognise a relationship anyway

D1 also likes that staff aim to preserve Case D's dignity where possible by informing her of their actions beforehand:

D1: They always ask her actually when they're gonna turn her over they always say to her "We're gonna turn you over is that alright?"

Care home: end of life plan

A DNR Form was completed in August 2011. Case D has been assessed as unable to make her own arrangements regarding the end of her life.

Case E Stage Two case study

Case E is a female in her late 80s. She has AD which was diagnosed in 2007.

Cognition

Case E has the capacity to make some uncomplicated everyday decisions regarding her care. She always recognises her family but has occasional difficulty communicating with others. She may be able to talk to a companion when in a one-on-one situation, albeit not always following the content of the discourse correctly. She has difficulty concentrating and will 'switch off' when in a group.

She can identify if she is in discomfort. She gets agitated and hits people with her stick sometimes as she thinks people are stealing from her. For example one day after breakfast at Care home #3, she believed that all the knives and forks were hers and became aggressive to those who she believed were stealing them. Therefore she requires staff intervention to manage her mental well-being, anxiety and behaviour.

Family history

Case E was born and lived in the same town where Care home #3 is located, although did live in other countries for a while with her husband. She married in the 1950s but was widowed after 50 years of marriage. She has two daughters and three grandsons. Case E and her family have enjoyed close personal relationships and she would regularly babysit her grandchildren.

Community life

Case E first displayed signs of dementia towards the end of her husband's life when she would often forget that E1 was to take them to the hospital for appointments. At that time E1 ascribed Case E's forgetfulness to the stress of looking after her husband. Approximately two to three years after his death it became more apparent that Case E had memory problems. She also displayed other symptoms:

E1: She'd phone up and say "I feel faint" and then you'd be sitting talking to her and she'd suddenly sort of go "I'm going away" try explaining that to a doctor and getting any sense they didn't know what to do one consultant said "Is she not faking it?"

Case E would tell people that she fainted and fell very frequently:

E1: She didn't actually faint she just wasn't with you and then she'd sort of come back and be fine but she didn't remember what she'd been doing just before it happened

Case E and E1 eventually visited a memory clinic for her symptoms. Healthcare professionals tested Case E for mini-strokes, fitted a pacemaker for an intermittent heartbeat and prescribed her a course at a falls clinic because of her 'falls'. She was then diagnosed with AD. The memory clinic advised for Case E to visit a day centre for people with dementia. Initially she did not want to attend but after the District Nurse attended with her for the first session she was more willing to go. She went once per week, and was picked up by the day centre's minibus. E1 felt this was advantageous for Case E:

E1: It did make a big difference because at least she was getting out of her flat a bit more... [at home] she was bored I could leave her doing some sewing or knitting but as soon as I left she used to put it down and then not start it again

Eventually Case E attended the day centre three days per week. As her dementia progressed she would forget she was waiting for the minibus and leave the house to buy a newspaper. However the drivers would usually return later to collect her. Initially, Case E lived alone in a four-bedroomed house with a large garden. Eventually the garden became too much for her to manage, which depressed her. E1 and her sister assisted some weekends, but had young families and households to care for:

E1: She did have a chap who came and mowed the lawn but she'd still look and say "Oh that needs doing and this needs doing" and also the house... it wasn't warm in the winter and I think she'd lost track of how the thermostat worked

Although she had in the past agreed to move house, it was only after her dementia was more apparent that E1 looked at alternative community residences for her mother. However because of her cognitive impairment Case E became reluctant to be involved in the process:

E1: To a certain extent she couldn't be bothered with the actual mechanics of moving so in the end we went and found and decided a sheltered independent living flat... it had pull-string alarms and a manager who lived in the building

The flat was on the first-floor as Case E refused to live on the ground-floor. The manager was not involved in any caring tasks for the residents but would help them with problems, for example telephoning a plumber or electrician for them if needed. E1 helped Case E with shopping and managing money, as historically her father had always managed the finances:

E1: She was never interested in money I certainly could not explain to her the difference between a debit card and a credit card I tried multiple times... she wasn't interested in the numbers

Although Case E was able to use cash and write cheques she could not learn to manage card payments.

At home: medical and sensory conditions

Case E takes, or took, Aricpet for her dementia. She has diabetes and takes Clopidogrel to inhibit blood clots. She has swollen feet and some leg discomfort at times. She visits an osteopath for her spine. She had bowel cancer in 2005.

At home: orientation

Case E experienced disorientation while living at home:

E1: Her timelines got totally confused she'd think she'd done something the day before [whereas] it was a week before

She would tell her daughter, for example, that she had sorted a plumbing issue in her flat but the next time E1 visited the problem had clearly not been fixed. She frequently became confused about things that she had or had not done, misplaced possessions and thought she had conversations with people she had not. She also had delusions:

E1: She told lovely stories there were little bits of truth in there but the joining bits were getting wilder and wilder and people would believe her

E1 became unable to trust Case E's word that she had performed housework and ADLs throughout the day and also whether she had washed and eaten:

E1: You'd have to [check] because you'd say "Have you have you washed that shirt" and she'd say "Yes" but you can guarantee that half the time she would have done and half the time she wouldn't

After spending half-term holidays with her teacher daughter, E1's sister, Case E would experience severe disorientation when back in her flat and would knock on other residents' doors late at night looking for her daughters.

Case E also became unsure of her social appointments and would telephone E1 every morning to discuss her plans for the day. E1 encouraged Case E to use a desk calendar placed next to her telephone to orient her to the date:

E1: It sat by the telephone and she'd get it go "My calendar says this" and we'd go "Yes that's right it's Monday it's this date" and she'd look "It says nine-thirty [day care] bus ride for [day care]"

E1 became used to frequent telephone calls as eventually Case E would telephone her up to ten times each day. Their conversations typically concerned orienting Case E and making sure she was safe:

E1: It got a bit more difficult maybe a year before she moved into [Care home #3] where she was getting a little bit more confused time-wise... she'd say "I'll go to bed now" and you'd say "No it's three o'clock in the afternoon" "It's three o'clock in the morning I should be asleep" more it was she'd wake up in the middle of the night and get dressed

At home: mobility

Case E's mobility when she lived at home was generally well. She could use stairs, albeit slowly, and left her house every day to go to the newsagents. As discussed in the 'Community Life' section, Case E worried about fainting and falling. Her GP then suggested she use a walking stick to give her extra balance if she felt faint. She already owned a walking stick her husband used when he was alive. The falls clinic adjusted the length of the stick to fit Case E and added a rubber stopper for grip. Case E used it when outside of her flat:

E1: It was more of a confidence thing than absolutely necessary... but at least we knew she had it with her

E1 perceives that Case E used the stick because she was told to by a healthcare professional; if she had told her mother to try a walking stick she feels that her mother would not use it. Case E preferred her walking stick to a generic hospital one because it looked unique. She had a telecare alarm in her new flat, but was prone to overusing this technology:

E1: Every time she went a bit funny over the night she'd pull the string [laughs] and we're going "No you can't keep pulling the string and saying you need an ambulance because" [laughs] but we got over that one [by saying] "Just phone me instead"

Her flat also had a handrail, as standard for the building, at the bath.

At home: washing

Case E typically only had one bath per week throughout her life because of her dry skin, but it eventually became apparent to E1 that Case E forgot her weekly bath and daily wash. E1 perceives that Case E at that time would have understood water temperature, but could very likely have started to draw the bath, forgot the taps were running and left the bathroom to flood. Case E was physically able to bathe and used the bath handrail as she got more nervous about her balance. The bottom of the bath was treated with a non-slip surface coating.

At home: grooming

Case E was able to perform grooming activities adequately when she lived at home. However as will be discussed in the 'Informal and formal carer assistance' section, eventually Case E was visited by a formal carer to ensure she was dressed and groomed.

At home: dressing

After moving into her smaller flat, Case E became unable to take care of laundry activities. She had always required a top-loading washing machine because of a bad back, and her new kitchen was unable to take this type of machine. E1 took care of washing most of her mother's clothes, bed-sheets and towels, although Case E could hand-wash some items. E1 had to check whether items needed to be cleaned because Case E became unaware when items were dirty. Similarly she tended to choose clothes to wear that she had worn the previous day, as they seemed more familiar to her.

Case E only had difficulties dressing because of her back, which impacted upon her lower extremity dressing such as tights and trousers. Over time she then wore skirts with pop socks to alleviate this problem.

At home: elimination

Case E had no difficulty with continence or toileting when she lived at home.

At home: eating

Case E could cook for herself most days although in the period approximately six months before her institutionalisation, Case E's time disorientation impacted upon her ability to perceive mealtimes. She never used any food from the freezer. E1 took her mother food shopping and learned to only buy small amounts of certain foods otherwise they would remain uneaten. E1 learned to check her mother's cupboards prior to food shopping; this way she was able to advise her Case E on the foods she already had when they were in the supermarket:

E1: She'd go round the shop and go "Oh I need some of that I need some of that" and when we got back to the flat I'd go to the cupboard to put it away and there were already three

Case E always trusted her daughter when she was told that she already had an item. E1 bought her mother a thicker-handled potato peeler but Case E preferred to use the one she had always used.

At home: informal and formal carer assistance

E1 assisted her mother with gardening, housework, food shopping and washing her clothes. E1's sister helped their mother with gardening, housework and to bathe once per week, under the guise of a normal visit, so as to not upset Case E if she knew it was a visit specifically to bathe her. E1 had previously tried to book a cleaner for Case E but she refused such help:

E1: Mother said "I don't mind my daughters helping but I don't need you thank you very much" and sacked her

Eventually, on the three mornings that Case E was to be picked up to go to the day centre, a formal carer visited her to ensure that she was awake, dressed, had eaten and was ready to leave. This worker was from a private formal carer organisation. E1 sourced the company based on recommendations from informal peer carers whom she had met at a carer's meeting that was run by staff from Care home #3. The formal carer would orient Case E, verbally prompt her to get dressed in clean clothes and prepare breakfast if she had not already eaten. Generally Case E accepted these visits and perceived the carers as friends. The carer let herself into the main flat buildings via electronic code but needed to knock on Case E's individual flat door to be let in; this led on some occasions to Case E's confusion and refusal to let her in. E1 was considering providing the worker with her own key, and for increasing formal care contact to include bathing assistance, but Case E was then relocated to Care home #3.

Relocation

Institutionalisation occurred because Case E began to get lost. This started when she began to get anxious about where she was going for Christmas Day in 2011. One evening in December E1 received a telephone call from a stranger who lived in Case E's deceased parents' house; Case E had somehow travelled eight miles to get there:

E1: She'd been to [day centre] that morning and they had lunch and then she got the bus to take her home she usually got home about half-past two but by five o'clock she had managed to get herself from [town] to [town]... because Christmas was coming and she'd been thinking about her parents

Then in late January 2012 E1 received another telephone call from two young men whose house Case E had arrived at. She had told the men that her daughter had dropped her off there as she lived there but was confused because her key didn't work in the door. Case E had E1's name and address in her handbag with which the men were able to contact E1:

E1: I just thought this is not safe anymore... somebody must have given her a lift and that is quite scary actually and we were very lucky that she turned up two sets of perfectly nice people who phoned me and made her a cup of tea kept her there 'til I sorted it out

E1 then visited Case E's flat every afternoon to ensure she returned from the day centre; this was extremely restrictive to E1's life and liberty. She also realised that an hour visit from a formal carer was no longer enough; Case E required more substantive care. With the added consideration of Case E's constant telephone calls to E1, she and her sister discussed their mother's potential institutionalisation. Although a difficult decision, they agreed that 24-hour supervision would ensure Case E's safety. E1 knew the manager and deputy manager of Care home #3 from the carers' meetings. She felt that Care home #3 was suitable because its locality would enable Case E to remain signed to her GP surgery and because she may recognise the area if she went out walking.

Case E relocated to Care home #3 in February 2012. She was not resistive to the prospect of relocating, although was told that her move was temporary while E1 went on holiday. She commented that she would be fine on her own because she was unaware of her risks relating to getting lost:

E1: We thought that would be the best way of getting her to actually go there in the first place her immediate reaction was "I don't need to do that I'm fine on my own" and she really

believed that and you know when we said to her when she went to her parent's house "How did you get here" she didn't really know

Care home life

Despite ulcerated legs Case E is an active individual and walks throughout Care home #3. She is generally physically-able and her difficulties with daily living are mostly related to poor cognition. For example she cannot recognise and remember what she needs to do to complete a task. She can also become fixated on items in the care home that she believes are her possessions:

K5E: She likes napkins... she says they're hers "I've made them" she has got a fixation on napkins and cutlery... she's a bit of a magpie or [maybe]it's just from [her] era in the war or whatever you don't know do you

She can easily become agitated if she believes others are stealing her possessions and has hit people with her walking stick at such times. She requires staff intervention to manage her well-being and anxiety. She can participate in social activities and go on day trips, although she has been known to take herself back to her bedroom for solitude during the daytime. She likes a whisky at bedtime, and typically sleeps well.

Care home: medical and sensory conditions

Case E has ulcerated legs which are dressed by the nurses at Care home #3. She also has reoccurring UTIs, for which she is encouraged to drink fluids to prevent. Case E is entirely reliant on nursing staff at the care home to administer medications, as are all of the residents.

Care home: orientation

Case E walks around the wings and lounges of Care home #3 as she pleases. This is allowed according to the organisational culture of the care home to enhance residents' sense of independence and preserve dignity; the main front door is electronically coded to prevent residents leaving unattended. Indeed, Case E is unable to leave the home on her own as she would be unable to find her route back. During her visits to Care home #3, E1 watches her mother when she goes to the bathroom to ensure that Case E will come back to her:

E1: Otherwise she doesn't always remember that she's got a visitor so she'll sort of wander off for a little walk wherever she fancies going so you have to [say] "Coming back to me" and she'll come back [laughs]

When she walks throughout the care home, she is generally oriented in familiar surroundings but sometimes cannot find her bedroom number.

Care home: mobility

Case E has a history of falls; in June 2013 she was found on the floor of her room trying to put on her shoes. She sometimes has help for transferring from carers but does not require a hoist unless it is to enter the bath. She uses the hand-rails in the bathrooms to make lowering and lifting herself on the toilet easier. She is supposed to walk with a walking stick:

K5E: She has one stick she only needs one but sometimes she walks with two and I've known her to have three at the same time [laughs]

However she sometimes forgets to use her walking stick and instead uses the hand-rails in the corridors. She only uses a wheelchair if out on day trips.

Her bed has a pressure-relieving mattress, and the bed height can be adjusted by controls. She has a call bell in her room but forgets to use it.

Care home: washing

Case E likes a long bath at night at least once or twice per week and soaking her legs in warm water. On other days she receives strip washes using the sink in her room with the help of carers:

K5E: She used to be able to do it by herself we have to help her now her needs have changed over the last couple of years

I: Do you only have to prompt her or do you do it for her?

K5E: Try to prompt her otherwise you're just taking it all away... she can still use her hands she feeds herself and stuff like that I let her do what she can

Case E can wash her face and upper extremities and receives assistance to wash the lower half of her body. Although agile, K5E perceives that Case E would become unbalanced and fall if she was to attempt to wash her lower extremities.

Care home: grooming

Case E does not have her hair set every week by the hairdresser as some residents do, but has her hair cut approximately every six weeks. Case E can comb her hair in the mornings but has a habit of pulling and fussing her hair so sometimes looks unkempt. She sometimes has assistance from carers to comb the hair on the back of her head.

Case E no longer wears make-up; E1 feels this is likely because she does not often go out. A podiatrist visits the care home to take care of Case E's toenail and feet. E1 sometimes files her mother's fingernails:

E1: She's never had manicures as a general thing so it wouldn't occur to me to give her a manicure... I'd be more likely to take her and have a cup of tea and sit and watch the fish she likes that

Case E can brush her teeth sometimes if prompted. Carers prepare her toothbrush with toothpaste and place it in Case E's hand close to her mouth. If she is very confused, the carers will provide full physical assistance.

Care home: dressing

Case E likes to be smart, clean and presentable at all times. She is proud of her appearance and enjoys accessorising with her watch and necklaces. She used to be able to choose the clothes she prefers but now requires assistance:

K5E: I will tend to sort of get [clothes] out or something that matches and go "Is that alright" and she might say she's not really that bothered she'll just say "That's fine"

She can dress herself, including her lower extremities. However carers should provide dressing assistance or monitor her clothing, as if she wakes up and dresses herself she will wear the same clothes day after day. Staff also monitor her because she has also been known to wash her own underwear and place it in her drawer while still wet. Case E sometimes wears her shoes and at other

times her slippers; E1 believes that this is because sometimes Case E feels like she is 'going out' when she leaves her room to enter the lounge. Her shoes and slippers have Velcro fastenings so they can be enlarged when she has bandages on her feet. However her footwear sometimes bothers her if the Velcro does not lie flat:

E1: She'll sit there and fiddle with them... if you pull the Velcro across too far because it doesn't quite meet... it annoys her so she'll sit there and try and poke it flat and you [say] "It won't go because there's no Velcro under there" [laughs] or else she very carefully lines the Velcro up but then of course her foot slides too far forwards

Case E may require some prompting and assistance to ensure comfort with regards to her body temperature; removing or adding clothes and blankets to remain comfortable.

Care home: elimination

Case E has a laxative for constipation when required. Although generally continent, she will soil herself if she cannot get to the toilet in time. She now wears continence pads held in place with net knickers in case of accidents. She is often taken to the toilet by care home staff to ensure that she has used the toilet properly, has replaced her clothes appropriately and has not used toilet tissue in place of a continence pad. She remembers to flush the toilet but does not wash her hands in the sink unless prompted by a carer. She does not remember to use soap unless it is handed to her.

Care home: eating

Case E has put on weight since entering the care home and her BMI indicates that she is overweight:

E1: If they provide food she will sit and eat it and occasionally she forgets that they've had lunch she'll say "Where's lunch" so they'll give her a biscuit or a banana or something... she's no problem as soon as you say it's food time she's there she's sat at the table waiting you know "Where's me dinner" [laughs]

Therefore, according to the care record and to E1, she currently experiences no problem with appetite or understanding her body's need for fuel. However, the interview with K5E indicated that Case E's appetite may be decreasing:

K5E: Her eating habits have changed... she doesn't eat half as much now... she might be a bit depressed... because she keeps saying she wants to die... [or] maybe she thinks [she's] back to being in the war or something it's just a waste

At the time of this interview, this suspicion had been reported by the care home nursing staff to Case E's GP, who was intending to visit Case E that day.

Case E's diet is of normal consistency. She can feed herself with normal cutlery although may need some assistance cutting food and opening cartons or bottles. She can use a normal mug, teacup and saucer or glass. In July 2012 a sore throat meant that she had problems swallowing. She had a pureed diet and thickened drinks until this improved a week later.

Care home: family visits

E1 has been involved with some day trips and taking her mother out to physiotherapist appointments, but mainly her visits consist of taking her mother into the back garden, watching the pet fish or playing Scrabble. E1 has noticed that Case E now has less patience with playing the board game and has difficulty remembering the rules. Case E can also easily grow tired and be reluctant to

finish a game. E1 has filed her mother's nails but rarely conducts any other grooming activity such as combing Case E's hair; Case E is usually awake and dressed when E1 arrives. She has been involved in Case E's continence needs and changes her pad if necessary. E1 now always takes spare continence pads from the home when taking her mother out for the day.

Care home: end of life plan

A DNR Form was in place from March 2012 a month after Case E's relocation to Care home #3. She has been assessed as unable to make her own arrangements regarding the end of her life.

Case F Stage Two case study

Case F is a female in her early 90s. She has VaD which was diagnosed approximately seven years ago. Her last MMSE gave her a score of two out of a total possible 30, as she refused to answer some of the questions.

Cognition

Case F first displayed memory problems when she lived in sheltered accommodation. In one incident she was distracted by the telephone while cooking; her poor memory combined with anosmia meant that she could not detect the gas in her house. A neighbour in the same block of flats detected the gas and turned off the oven. After this event, F1 accompanied his mother to her GP. They were referred to a memory clinic at the local hospital and she was diagnosed with dementia.

Currently Case F can make some uncomplicated decisions regarding daily life. She could inform others if she was being abused, although because of immobility would be unable to walk away from a harmful situation. She is generally placid although may 'lash out' when being transferred in a stand-aid hoist onto a toilet. She is sometimes able to hold conversations with carers but often will not follow the discourse well:

K6F: When her son comes she can have a laugh but he'll say something to her and she won't understand after... he even says "I don't think she understands what I say"

Family history

Case F was born in a different part of the country to Care home #3. After joining the army in 1939 she met her husband in hospital in Europe and married in the 1940s. They lived in the same county as Care home #3. She has one son, F1, and one nephew. She has been widowed since 2002. Her husband was in a care home for the last few years of his life. The experience of finding a home for his father helped F1 later when he searched for a care home for Case F.

Community life

Case F sold the family house and moved into a sheltered housing flat with a warden; she lived there for a number of years. The previous tenants were blind and wheelchair-bound so the property already had hand-rails in the bathroom around the sink and the toilet had a raised, white seat.

At home: medical and sensory conditions

In addition to her memory loss, Case F suffers from: osteoarthritis, hypothyroidism, high cholesterol, diabetes, and TIAs. She had angioplasty surgery. She has glaucoma and sore eyes. She has suffered chest infections and problems with breathlessness on exertion and rest, so has an inhaler. These may be linked to her history of smoking.

At home: orientation

Case F began to get lost frequently when outside. This led to her institutionalisation so is described below in the 'Relocation' section.

At home: mobility

Case F began to suffer mobility problems while living at home. An OT visited her in her flat to assess her and the environment. Case F's impaired walking was alleviated first with the use of a calliper, then a walking frame. This was sourced from 'the local health service' according to F1, although the family also had an old one that had belonged to Case F's husband. Case F adapted very quickly to using a walking frame; F1 speculated that she was used to the presence of the technology because

of her husband's previous use of it. Soon however Case F required more assistance than the walking frame could provide:

F1: It was getting worse and worse... over a few months it was obvious that she'd rather be sitting in the wheelchair

Case F did not use a wheelchair when in her flat as she could use the hand-rails and furniture to balance. She used either her light-weight wheelchair or electric scooter when on outings and shopping. The warden at Case F's sheltered housing advised F1 where to obtain these items.

At home: washing

Due to Case F's impaired mobility, the local Age Concern advised turning Case F's bathroom into a wet-room. This change was partly funded by Case F. The transformation was beneficial for easing Case F's difficulties with washing, although she was not allowed to use the wet-room alone. At this time she was washed by formal carers; more information on these carers is provided below in the 'At home: informal and formal carer assistance' section.

At home: grooming

Case F could perform grooming tasks such as combing her hair, brushing her teeth and applying make-up.

At home: dressing

While living at home Case F could dress herself.

At home: elimination

Case F rarely experienced toileting or continence problems while she lived at home. Although she suffered with poor mobility, she could usually get to the bathroom in time. However there were some instances when F1 or his wife had to change Case F's bed-sheets after she had soiled them. Case F also sporadically suffered UTIs which F1 recalled increased her confusion.

At home: eating

F1 remembered that Case F always seemed to be hungry when living in the community. She had no decreased appetite. She could heat up frozen meals and prepare drinks, although often let formal carers prepare meals:

F1: She likes a cup of tea... dare I say it she's quite a lazy woman if she knew there was somebody else coming in to do something she'd be the first one to sit back and let somebody else do it [laughs]

At home: informal and formal carer assistance

Case F already received some assistance from formal carers at the time of the aforementioned gas oven incident. An OT assessed Case F's mobility and recommended that she have formal carer assistance. F1 was provided with a list of formal caring services by the local council. Case F had a clash with the staff of the first company they used so they switched to a second organisation who were more suitable. Formal carers visited Case F every morning to help her get out of bed and every night to ensure she had taken her medication, she had eaten and to help her back into bed. Carers only prepared food for her in the last few months of her time living at home.

F1 helped his mother to go food shopping weekly, take her out on outings and organised medication deliveries from the local chemist. He acknowledged that he would have been prepared to help his

mother with ADLs if required but the formal caring package was already in place to meet those needs.

Relocation

After Case F's mobility declined, she was frequently hospitalised due to falls. She also began to get lost, and was once found outside her block of flats disoriented and confused. The combination of falls and becoming lost led to a relocation decision:

F1: It became obvious she could not live on her own

Although F1 prompted the decision, he did talk to his mother about the situation:

F1: I don't think she really cared... she [was] obviously getting sick and tired of going in and out of hospital... not knowing why she was there

F1 visited many care homes from a list provided by the local council. He chose Care home #3 because it did not smell offensive; for him this was a key feature when deciding between care homes:

F1: It's a small thing but a very important thing I think... not only for the person staying but the person visiting not wanting to visit because "I've got to go to that smelly place again"

However, Case F had also visited Care home #3 on a previous occasion when F1 required some respite. This also therefore influenced his final location decision. Case F relocated to Care home #3 in March 2009 and settled well:

F1: I'll always remember her first day here when she asked a carer for a wine list with her first meal at lunchtime which I saw as a pretty good sign... she doesn't really mind at all now I don't think she really knows where she is

Care home life

Case F's cognitive impairment has declined further in the years since her relocation to Care home #3. She requires support from others to communicate her needs; staff must ensure that they eliminate other noises when speaking to her so that she can hear them. They must explain procedures clearly and give her time to ask questions. Carers must provide assistance for her to fulfil social needs and to attend religious services. She used to be able to participate in social activities such as chair dances. Now she enjoys singing old war songs and joining in with a tambourine. Case F rarely displays any signs of anxiety or depression but has recently developed mood swings:

F1: She's always happy-go-lucky... but recently apparently she has occasionally hit out [at] one or two people in the evenings when she's being bathed... it's difficult for me to tell my mother not to do it because I'm afraid she's past that

Care home: medical and sensory conditions

The care home staff are aware of Case F's historical and existing co-morbidities and are able to manage these accordingly. For example they know to keep her inhaler nearby and to discourage Case F from rubbing her eyes, which would worsen her glaucoma.

Care home: orientation

Case F is sometimes oriented in familiar surroundings but would be unable to find her way back to the care home if she went out for a walk. She can no longer find her bedroom from the lounge even with environmental prompts in place such as room signs.

Care home: mobility

When she first relocated to Care home #3, Case F could mobilise using a walking frame. Her mobility is now poor and she has a history of falls; she wears hip protectors and mainly uses a wheelchair. Both F1 and her keyworker, K6F, perceived her decline in walking ability to be as a consequence of cognitive impairment as much as physical impairment:

F1: She's forgotten how [to walk] and indeed because she's not strong enough

K6F: Both really if we put her in stand-aid hoist say "Come on [Case F] stand" sometimes she will sometimes she won't she's not registering what we're telling her to do sometimes

However they perceived that Case F's balance and upper extremity mobility to be relatively unimpaired. Two carers transfer her using a stand-aid hoist with large-sized sling. Case F is not distressed whilst she is in the hoist nor bothered by her hip protectors. She is transferred from her wheelchair into a recliner chair when in the care home lounge; this chair elevates her legs as she is required to do. A slide-sheet is used to reposition her when in a chair or in bed to compensate for her poor mobility. However she is still at risk of rolling out of bed so it is kept at the lowest level possible. A sensor mat is placed on the floor during the night. She has a call bell and bed-rails.

Care home: washing

Case F receives assistance with all personal hygiene activities. She used to be able to wash the top half of her body alone but now requires assistance from one carer to wash her whole body. This difficulty was attributed by K6F to Case F's cognitive impairment rather than physical difficulties. Case F receives help to have a full shower and to wash her hair once per week. Although she is happy to receive washes from female or male staff, she may be un-co-operative during washing:

K6F: If we give her the flannel she might go like that [mimes some wiping] but otherwise sometimes "Get off me"

Her Waterlow Pressure Risk Assessment signifies that she has a Very High Risk of pressure sores due to fragile skin and urine and faecal incontinence. She has a pressure mattress on her bed to prevent skin sores, and carers cream and elevate her legs regularly.

Care home: grooming

Case F visits the hairdresser at Care home #3 weekly. She receives assistance with her nails and likes to wear nail varnish. A podiatrist visits her at the care home; she pays for this service. Information about whether she does or does not wear dentures is conflicting.

Care home: dressing

Case F requires total support from carers to dress and to regulate her body temperature. Staff give her choices of clothes but she does not always communicate her preferences:

K6F: We always give her an opportunity when you get them out the wardrobe you say "Would you like to put that on" she'll say "Yeah" or [she is] not bothered you could pick anything out for [Case F] and it wouldn't bother her

She sometimes resists when she is dressed, displayed by pulling her arm away. The type of clothes she wears has changed over time, particularly with the introduction of elasticated-waist skirts to eliminate a barrier to bladder evacuation.

Care home: elimination

Case F is now incontinent of urine and faeces and cannot detect when she needs to eliminate. She wears different pads for day and night, typically using three Maliform Plus during the day (absorbency 720ml) and a Maliform Extra at night (absorbency 960ml). During the day staff physically assist her to the toilet at regular intervals, using an input and output chart to monitor her fluids, in an attempt to prevent soiling. The help her get to the bathroom in good time, manage the removal of her clothes and to sit onto the toilet. She sometimes resists this assistance:

K6F: She has lashed out before trying to fight when we're pulling her knickers down saying "Get off me don't do that" [we say] "[Case F] we're putting you on the toilet seat use the toilet" "Get off me get off me" but if we don't do it she will be soaking wet

The total assistance provided to Case F with toileting includes cleaning her after elimination and washing her hands as she can no longer perform these tasks.

Care home: eating

Case F's weight has reduced since she entered Care home #3, taking her from obese to overweight according to her BMI. She has diabetes which is managed through diet. The kitchen staff are aware that she has a 'sweet tooth' so make sugar-free cakes for her. She no longer eats normal-consistency food and has a pureed diet. K6F attributed this to her sore gums and reluctance to chew. She will however suck a biscuit when sitting with her son. She used to be able to feed herself with verbal prompting from carers and their assistance to cut her food into manageable pieces; now only on a good day can she use cutlery. She is usually unmotivated to feed herself and allows the staff to feed her. She can use a teacup and saucer or glass, although sometimes has an adapted beaker with two handles. She can recognise if she is thirsty or hungry.

Care home: family visits

F1 and his wife used to take Case F out on long day trips. They managed her toileting activity well, having spare continence pads and a travel-version of a raised toilet seat to aid her mobility. Now he may take her out but only for short trips such as the garden centre or for lunch due to her reduced mobility. F1's visits to the care home do not concern morning ADLs such as washing and dressing, as these tasks have already been conducted with Case F by the time he arrives. His visits now consist of social leisure time: walks around the care home garden, chatting, tea and biscuits. He perceived that his mother does not always understand what he says but still enjoys the time he spends with her. He buys her toiletries or clothes when required.

Care home: end of life plan

A DNR Form was completed in March 2012 owing to the likelihood of a poor quality of life in the future and after CPR. She has been assessed as unable to make her own arrangements regarding the end of her life.

Case G Stage Two case study

Case G is a female in her early 90s. She has AD, which was diagnosed three to five years ago.

Cognition

The first sign of Case G's dementia was memory loss, particularly forgetting where she had put personal items. Over time she began to lose insight into her own condition, and that of her husband who also had dementia. She became unable to anticipate and respond to her husband's care needs. She was also confused about his inactivity due to poor mobility:

G1: Sometimes she called the ambulance because he was sitting there and doing nothing so she was confused about that

She would telephone her sons multiple times per day and leave identical answerphone messages. She was diagnosed with AD after G1 accompanied his mother to visit her GP and they were referred to a memory clinic for a brain scan and MMSE.

Case G now has fluctuating capacity depending on the decision that needs to be made and was the only resident in this study to possess the capacity-to-consent for her care record to be mapped for this research project. Her main cognitive problems are recall and language, although she can communicate with others.

Family history

Case G has two living sons and a third who died when a teenager. She has four grandsons. Case G cared for her husband for approximately 15 years after he had a stroke. His mobility declined rapidly and he fell frequently, he lost his ability to speak and developed VaD. Eventually formal carer assistance helped him with personal care ADLs and continence management. Case G's acceptance of the carers was reluctant:

G1: She was terribly independent didn't want carers didn't want anyone coming into her house and was quite adamant that she was capable of looking after him which she was to be fair until she declined

Community life

Case G lived in the community with her husband until they together relocated to Care home #3 in 2011. While living at home Case G was very involved with her local church. She had lived in the same family house for a very long time and it was ill-equipped for her husband's declining mobility. It was a two-storied house with no downstairs bathroom. An OT assessed Case G's husband and hand-rails were installed on the front door, at the inner doors and on the stairs. They also provided commodes, stands to raise his armchair and trialled a stand-aid hoist. Continence pads were supplied through healthcare services. G1 perceives that his father placidly accepted the new use of technology whereas Case G was reluctant because of the disruption. Case G's husband at times became verbally and physically aggressive towards her because of his frustration at his inability to communicate. Due to her own dementia, Case G could not perceive that her husband had any difficulties.

At home: medical and sensory conditions

Case G had osteoporosis and arthritis in addition to AD whilst living in the community. She was prescribed Aricept for her dementia. Case G could not remember to take her medication and was unable to use a pill-box AT.

At home: orientation

Case G did not display disorientation around her house. G1 purchased a large-button telephone for Case G; she was able to use this as the device had G1's telephone number on a recall setting. However he feels that she abused this as she would call him frequently. G1 was not as successful when trying to teach Case G to use a new microwave even though it only had three buttons:

G1: Keeping it very simple and she'd say "Oh yes yes that's easy" and of course as soon as I wasn't there she couldn't do it

No dementia-specific ATs were used to aid Case G's memory. However Case G used a calendar, a tactic she had always used, to remind her of appointments. G1 also set up a notepad for Case G to write a shopping list, the formal carers' names and forthcoming events:

G1: But I'm not sure that she really looked at that... maybe a little memory jogger [G1 is referring to a 'smart' memory device] might have got her to do things

At home: mobility

Case G was not immobile while living at home although had a stiff left arm. She was not at great risk of falls there, but did have a pendant alarm. However she rarely remembered to wear it:

I: Was it that she thought it was ugly?

G1: No she recognised it because her sister had a fall and was left for two days so she knew it was important but she just forgot I guess

At home: washing

G1 perceives that Case G was likely not washing herself adequately, nor was she able to ensure her husband was washed. This problem was only alleviated with formal caring assistance as is described below in the 'Informal and formal carer assistance' section.

At home: grooming

Similarly, G1 also perceives that Case G was probably experiencing difficulty performing and remembering to perform grooming activities. In particular difficulty with washing her hair because of her stiff arm:

G1: We couldn't be absolutely sure except she never went to the hairdressers and she had her hair long so how she was washing that... there was no sign of her having washed her hair

At home: dressing

While living at home Case G was able to dress herself.

At home: elimination

In addition to continence pads from healthcare services, G1 obtained continence products for his father from the local mobility shop. These products included mattress, duvet and pillow covers, rubber bed sheets and rubber cushions. Case G did not have toileting or continence problems.

At home: eating

Case G had difficulty with the IADL of preparing food for her husband and herself. She was not physically too weak to prepare the food but did not remember to do it:

G1: She'd say "Right what do you want for dinner" and he'd say "Er mmm" "Do you want egg and chips?" and he'd say "Yes ok" and then [later] I'd say "Are you gonna do lunch for dad?" and she'd say "Oh I don't think he's told me what he wants" so she'd go back again and this would go on so I'm thinking when I'm not there she's probably not getting him anything

Her husband had a swallowing and reflux problem that also meant he spat out or regurgitated food. It was a diagnosis of malnutrition in Case G's husband that first indicated to others that both she and her husband possibly had dementia. They eventually both received meals-on-wheels services.

At home: informal and formal carer assistance

Both G1 and his wife tried at times to conduct intimate assistance with Case G, particularly for washing. Case G refused assistance from others but let her son and daughter-in-law provide intimate care for her husband. G1, his wife and his brother conducted some tasks such as food shopping and laundry for their parents. Formal social care services also became involved after G1's father was in hospital with malnourishment. Case G accepted her husband's two-week re-ablement care package:

G1: We told her "You've got no choice it's the hospital" so she accepted that saw it as an extension of his treatment

However, Case G was reluctant for the two to receive formal care assistance after that fortnight. She refused to be referred to a day centre and discouraged her husband from attending. G1 arranged formal caring for his father through the same agency who had provided the re-ablement package:

G1: She was resentful didn't want them in... she'd complain but she accepted it

Her husband's carers entered their house twice per day to assist with morning and evening routine including his continence care. After an arduous process G1 was also eventually successful at arranging the same carer to ensure that Case G took her dementia medication. At this time Case G's dementia worsened; she began to get confused and accused the carers of stealing from her. She began to hide her possessions inside her pillow, for example: her handbag, all of her underwear and cleaning products. She began to mistake visitors' identities and forget they had been to see her. She became depressed and would cry frequently. She also began to refuse to go out for her weekly lunch with her church friend. Case G had always been known to be very house-proud, but as her dementia progressed she would forget to conduct cleaning activities and ADLs:

G1: She didn't change her bed although when I'd ask her "Oh shall I change the bed?" "Oh I'll do it Wednesday" she'd always say "I did it last Wednesday" "Have you washed your hair?" "Yes I did it last Wednesday"

G1 then arranged for the formal carers to perform dish-washing and load the washing machine with dirty laundry. He also arranged for Case G and her husband to receive meals-on-wheels. This had been a struggle; at first only his father had been eligible because of his malnutrition. However this had occurred because Case G did not remember to prepare food for the two; G1 eventually successfully arranged for them both to receive the service.

Relocation

Case G and her husband relocated together to Care home #3 in September 2011. The relocation occurred after a discussion G1 had with Case G's GP about his father's increased physical impairment and Case G's disturbed sleep due to looking after her husband:

G1: He said "Well they probably need twenty-four hour care because there's two of them and she's not gonna be able to cope with him"

Although G1 and his brother then spoke to Case G about 24-hour caring services in their home, she did not want a permanent carer in the house. G1 was also reluctant for more intense formal caring services in the community as he felt the carers were untrustworthy. He and his brother tried multiple times to persuade Case G to let her husband enter a care home:

G1: Then we started taking nasty tablets we said "Look we really don't think that you can look after dad and it's not fair on him he's not getting the care he needs he's being neglected"

Case G then agreed that her husband should relocate to a care home but only on the grounds that she move with him. It was difficult for G1 to find a suitable home that could take both Case G, who had only cognitive impairment, and her husband with both cognitive and extreme physical impairment:

G1: A lot of them didn't want someone like my mum because she was too early-stages they were specialised dementia units which were no good for her... and the ones that would accept my mum would not accept my dad in case he got worse [physically]

Care home #3 could accommodate the couple. On relocation day, Case G was emotional and refused to get her things ready.

Care home life

The couple moved into separate rooms in Care home #3 to ensure that Case G had undisturbed sleep. They did not initially settle into the care home well. Case G's husband died approximately five months after institutionalisation after falling unwell. This was a traumatic experience for Case G and caused her depression and anxiety. As the relocation had been prompted by his father's poor mobility, G1 then considered the possibility of moving Case G back to her own home:

G1: She would have needed a bit more care and [her] home was in an awful state... they'd had nothing done for twenty years there's no downstairs loo or anything and it was pretty disgusting... we decided that as she was declining it made sense not to uproot her

Moving Case G to a new location such as assisted living facilities would have caused her further confusion and disorientation. It was decided that Case G would remain living at Care home #3.

Her cognitive and physical impairments have declined since relocating to the care home but Case G can communicate her needs, likes and dislikes. Her ability to follow and hold a conversation fluctuates. In the morning she likes to stay in bed late and have a cup of tea first thing. She is more likely to be in a low mood or confused in the mornings and has recently become more reluctant to leave her room. However if she is in a good mood she likes to laugh with the other residents:

K7G: If she's in one of her "No you've dumped me in this place I'm not coming out" there's not a thing in the world will get her out [of her bedroom] but if she's in a [good mood] we say "Come on come out they're having a knees-up in there" or something like that she'll come straight out and she'll enjoy it

During night-time routine she can take herself to bed. Her sleep pattern is generally undisturbed but she prefers her bedroom door to be open. Overall G1 feels that the institutionalisation decision was the right one:

G1: She's a lot healthier put on weight she's getting all the washing... she looks much better than she has for years

Care home: medical and sensory conditions

In addition to the aforementioned co-morbidities, Case G currently has her blood pressure monitored frequently.

Care home: orientation

Case G is oriented in familiar surroundings but could not leave Care home #3 on her own:

G1: She'll get from her room to the lounge and into the communal room she can do that although yesterday she was slightly confused about whether to turn left or right... and I said "Well which way do you think?" she said "Oh that way" I said "Yes" but she doesn't accept that there is a problem

She is sometimes upset when she can't remember the day or time and has been known to confabulate to compensate for her memory loss:

G1: She makes quite a convoluted excuse as to why she doesn't remember something

She often misplaces objects. She also sometimes forgets that her husband has died and asks both her son and the staff his whereabouts:

G1: Wandering around looking for him... so you have to go through the "Dad's dead" discussion... that was tough but the good thing was that she'd forget that she was upset

K7G: She still does now "Why did he leave me"

Case G has little insight into her dementia or disorientation.

Care home: mobility

Case G has arthritis in her shoulder and some back pain. Although mobile, Case G is prone to falls but refuses to wear hip protectors. She sometimes does not believe the staff when she is told that she fell. She never used to use walking aids, nor AT for moving and handling. However she has become more impaired when walking and begun to lean to one side. For the first time she recently used a wheelchair when on an outing that required a lot of walking. She is usually reluctant to walk around the care home garden. She sits throughout the day and her inactivity has started to worry G1.

Case G has a call bell in her room which she is encouraged to use but doesn't remember to. She does not require bed-rails but has a sensor mat in case she falls from or leaves her bed during the night.

Care home: washing

As Case G had a history of refusing help with hygiene activities, the care home staff slowly encouraged her to accept care for washing:

G1: They were very good they didn't sort of throw her in the bath first day they sort of worked on it over two or three weeks

Case G now receives full assistance with washing and bathing from the care home staff:

K7G: We try and encourage her to wash her face and her hands... you have to prompt her to do it... but she's got a bad shoulder so we have to do really most of it for her

She also receives showers. This has a seat to eliminate the need for the user to stand up. The seat also tilts back when necessary for ease of washing. However Case G still sometimes refuses showers.

Her Waterlow Pressure Risk Assessment showed that although she is fully mobile, she is at Very High risk of pressure ulcers and she has suffered with cellulitis in her legs. Her skin is creamed regularly.

Care home: grooming

Over time Case G has needed increased levels of human assistance with grooming activities. At first supervision, then prompting and now full physical assistance for shaving, nail-care, and oral-care. A podiatrist visits to cut her toenails. She has a weekly hair set at the care home's hairdressing room. She can still comb her hair when required. She no longer wears make-up.

Care home: dressing

Case G likes to be presentable and smart before leaving her bedroom. She chooses her own clothes but requires assistance and supervision by one carer to get dressed due to her arthritic shoulder. She can use buttons unless they are small and has trouble holding small zips. She can put her shoes on using a long-handled shoehorn, although now usually wears slippers because of swollen ankles. Case G has no difficulty gauging and managing her body temperature. Case G does not understand the laundry system at the care home:

K7G: She's reluctant for anything to go down the wash so we normally have to sneak it out or [laughs] say "Well let me just freshen it up then" and [she says] everything's been gone for days which it hasn't it's been gone for a morning

Care home: elimination

Case G is occasionally incontinent of urine. She wears continence pads day and night but also sits on her newspaper when in the lounge as she is worried about leaking urine. She is not entirely comfortable with the thought of wearing the pads:

K7G: She always says "Oh they stink" and I say "It's just them little dribbles" she goes "Oh I suppose you're right you know best"

She has no history of constipation or UTIs. She uses both her en-suite and the communal toilet by herself although is encouraged to use the call bell in her room so that staff can ensure her safety.

Care home: eating

Case G has a BMI of 26.4kg/m² which puts her as slightly overweight. She has put on weight since relocating to Care home #3 but according to G1 looks better for it. Indeed, he perceives that she was rarely eating when she lived at home because she did to remember to prepare food.

She eats a normal diet. Although she did not eat well due to depression after her husband died, now her appetite is good and she can detect if she is hungry. Case G can identify the foods she wants

based on the menu list and normally eats lunch with the other residents in the dining room although always has breakfast in her room. She can use cutlery and feed herself, although may require assistance with cutting food and opening cartons and bottles. She can identify if thirsty and does not require adapted drinking vessels.

Care home: family visits

G1 obtains toiletries and other items his mother requires but does not perform ADL assistance for her. He takes his mother out on day trips; they are able to do this now her husband has died as before she would not leave him alone at the care home. As Case G has lately become more tired and imbalanced when walking so they used a wheelchair on their most recent outing. Residents and family are allowed to borrow wheelchairs from Care home #3 when required. The main disadvantage of taking Case G out is her disorientation on return:

G1: If you've been out for more than an hour or so she'll think she's going back to her old house so you go through the trauma of "Where are you taking me?" again so you think "Oh God is it worth it"

However G1 feels that the time he now spends with his mother is better quality time together than when she lived in the community and his time with her consisted of housework.

G1's brother visits his mother in the care home less frequently than G1. He visits approximately once per month:

G1: He takes the view that if she can't remember he's come why should he bother... it's that sort of "Don't like hospitals don't like old people"

Care home: end of life plan

A DNR Form was completed September 2012, to be reviewed in September 2013. Notes on the justification for the order state that this was completed because Case G's AD means that her quality of life would not improve after CPR. It was also confirmed by her sons that she had previously stated that she would not want to be resuscitated. She has been assessed as unable to make her own arrangements regarding the end of her life.

Case H Stage Two case study

Case H is a female in her early 90s. She has VaD which was diagnosed approximately eight years ago.

Cognition

Whilst Case H and her husband lived together in the community she began to demonstrate forgetfulness and mood-swings. Her husband was reluctant to make healthcare authorities aware of Case H's memory problems but they eventually visited their GP. They were referred to a Community Psychiatric Nurse (CPN). Once they were under the charge of the CPN, her husband was reluctant for Case H to have a brain scan as he thought that Case H would be taken away from him. Their daughter, H1, had to plead with the CPN to be clearer about Case H's condition; that is, give a formal diagnosis:

H1: I pleaded with [CPN] he said "Why do you need to put a label on it" I said "Because it will help me know what I'm doing what's going on" and he said "You know we don't want to put a label on it" I said "I don't care I want to know what this is" so they did the test

Case H was unable to continue her most recent MMSE as she became tearful. Currently she has fluctuating capacity when making decisions as she finds it difficult to retain information. She has limited language for expressing her needs as her speech is sometimes incoherent. She can often be depressed, agitated and aggressive. These behaviours are managed by: medication, minimising her triggers and monitoring mood swings. She has 'good days' when she is more lucid and 'bad days' when she can be very uncommunicative.

Family history

Case H was married and widowed in the 1940s. She has one son from this marriage. She re-married and had two daughters, one who died in childhood and H1. She and her husband also adopted a daughter. There have been many family tragedies throughout Case H's life. She has many grandchildren and great grandchildren. Case H was widowed in the late 2000s after 59 years of marriage. After his death it became more apparent to H1 that her mother required more assistance than she had perceived.

Community life

Case H and her husband lived in the four-bedroomed family home they bought together in the 1950s. She was a house-proud woman and had interests in cordon bleu cookery and dress making. She worked part-time as a silver service waitress whilst the children were at school. She was always extremely physically fit.

As she and her husband aged Case H became less able to cope with housework. This was due to declined cognition rather than immobility. She was forgetful and aphasic. Her husband began to perform food preparation and laundry activities. He also made sure that they left the house every day, walking or visiting parks:

H1: They were quite able-bodied I think dad probably realised that was good for her and if he took her out of the house in the morning... then he could keep her going and she wouldn't worry about things

She also attended a lunch club once per week. After her husband died, Case H remained officially living in her home for approximately two-and-a-half more years, although the last 18 months of this were on a hospital ward. The Relocation section below has more details.

At home: medical and sensory conditions

H1 noted that Case H's history of TIAs may have contributed to her VaD. In addition to her dementia Case H has arthritis in her right shoulder. She is sometimes 'chesty' and breathless so has an inhaler twice per day. She can be susceptible to chest infections. When she has a chest infection she can have trouble swallowing. She also took both an anti-psychotic and an antidepressant to manage her mood-swings and depression.

At home: orientation

Case H was not generally disoriented when she lived at home. She got lost once, was found by local police and was sectioned after being aggressive towards them.

At home: mobility

Case H had some difficulty with gait and balance. She was able to use the stairs. Her house was not modified to assist her physical impairments but it already had grab-rails and a downstairs bathroom due to a long-term injury sustained by H1 as a young woman. She also already owned a bath-lift which had been bought to assist her husband into and out of the bath.

At home: washing

Case H had little physical difficulty washing or bathing when she lived at home although her poor impaired her ability to remember to perform such activities.

At home: grooming

Case H was able to physically perform grooming activities whilst she lived in the community although her memory loss meant that she later received assistance with getting ready in the morning.

At home: dressing

As time progressed Case H had difficulty dressing herself due to her arthritic shoulder but could use buttons and zips.

At home: elimination

Case H was able to perform toileting activities and was fully continent.

At home: eating

Over time Case H had assistance to prepare breakfast although could usually manage to prepare other meals. She was able to perform eating tasks adequately and could detect her hunger or thirst.

At home: informal and formal carer assistance

H1 sometimes shopped for food for her parents but her father performed most of the housework. As Case H's husband was reluctant to admit that his wife memory problems, they did not receive the formal domiciliary help they may have found beneficial. H1 feels that social services missed an opportunity to ensure that the dyad received help:

H1: There was people realising that there was something wrong why couldn't somebody have... taken him to one side and said "[Father's name] we think you need more help" I mean he was doing so much ok he was seventy-seven which is a good age but he could have gone on for a lot longer if somebody had done something about it

However H1 also acknowledges that Case H would have been extremely stressed if strangers were in her house and it would have been necessary to formulate an elaborate plan to arrange a cleaner:

H1: He'd have had to wait until he took her out then phoned [the cleaner] and say "Yes you can come now and do the housework" and dad was very proud he wanted to do it himself I can remember he said "After all the things we've been through as a family and we've coped with it all I'm watching over her"

Therefore, both Case H and her husband were not conducive to domiciliary caring services. However after she was widowed H1's brother and his wife arranged for formal care services to visit Case H twice per day. She did not like their presence and would sometimes refuse them entry to her home. She struggled to understand the carers' foreign accents, and as her dementia worsened she became more verbally aggressive and racist towards them. She only wanted H1 to assist her. The formal carers helped Case H through morning and evening routine including washing, dressing, grooming and preparing breakfast. They verbally encouraged and prompted her through these activities rather than provided physical assistance:

H1: She was quite physically well at that point... but she needed somebody to remind her that she needed to get dressed she needed to wash she needed to do her teeth

The carers also ensured that Case H took her medication.

Relocation

Case H's life immediately prior to relocating to Care home #3 is complicated. Approximately a year after her husband died Case H was sectioned for a second time in hospital following aggressive behaviour towards H1. She lived at the hospital for approximately 18 months. The hospital staff, Case H's CPN, H1 and H1's brother all perceived that Case H was unable to live at home due to her cognitive impairment and poor mental health. There were also fears that she would be physically aggressive towards formal carers in her home. She was institutionalised to a care home. Approximately six months after, she was sectioned in hospital for a third time following an aggressive incident towards a fellow resident. She stayed at the hospital for one year. Her previous care home was unable to cope with her behaviour and unable to provide nursing care so she moved to Care home #3.

Care home life

Case H has resided in Care home #3 for approximately two to three years and has now reposed to life there:

K8H: When she first came in here ... she could be a little bit aggressive towards the staff she's settled down a lot now she's more co-operative with any care we give her

As long as staff explain clearly to Case H the actions they are about to take with her, for example that they are going to hoist her, then she understands and remains calm. She used to bite and fight the staff but now enjoys cuddles and such physical comfort from them. Indeed she has a cuddle first thing in the morning to calm her down and get her in a good mood as she doesn't like getting out of bed.

When she first lived at the home Case H thought she lived there and would talk to the residents as if she were a staff member. Now as her physical impairments and aphasia have progressed she cannot walk around the home or hold a conversation. However she can demonstrate that she understands others' speech through her body language. She sleeps a lot and goes to bed early. She requires a high level of support from carers to take part in activity programmes and fulfil her social needs.

Care home: medical and sensory conditions

Since living in the Care home #3 Case H has experienced breast cancer and a shoulder dislocation from a fall. She has swollen lower extremities so staff must ensure that she elevates her legs when sitting in the lounge or in bed at night. H1 believes that Case H no longer takes her antipsychotic or antidepressant medications. Her hearing is good but staff must speak loudly to her. She has spectacles to read and watch the television and has difficulty judging distances.

Care home: orientation

Case H is now disoriented to people, place and time. She can be severely bewildered by everyday events.

Care home: mobility

Due to physical impairments Case H now has difficulty during gait and transferring. She shuffles her feet when walking, has difficulty weight-bearing and balancing. Due to cognitive impairment she has visuo-spatial problems and also forgets the risks of standing-up unaided; she therefore has had some falls with subsequent significant injuries. Case H used to use a walking frame but now has a wheelchair. She can stand with the aid of two staff and a walking frame, but carers more often use a stand-aid hoist and sling for transferring activities.

Her bedroom has an adjustable bed which is set at the lowest level in case she falls out or tries to stand up. There is a pressure alarm-mat on the carpet next to her bed to alert staff if she stands. Bed-rails have been assessed as inappropriate because she can climb onto and out of bed. Therefore there is a greater risk of injury if she were to climb over the rails than if she were to get out of bed. However K8H claims that generally Case H is aware that she is not to get up out of bed unaided. Case H would be unable to use the call-bell in an emergency:

K8H: Even if you explain to her I don't think she would understand that [it] would get help

Care home: washing

Case H receives assistance to get washed. She usually has a daily strip wash and a shower or bath once per week. She used to be able to wash her face, upper body and arms with a flannel. Now she is happy for carers to wash all aspects of her body:

K8H: We try and give her the flannel for her face but recently I think she's quite happy for us to do the care now it's like she's resigned herself to the fact that "Just do it just get me up" so we do everything really

She is hoisted into a shower chair or commode to make washing or showering easier for her and the carer. She sometimes uses the automatic bath that hoists her into and out of the tub. The hoist includes a lap belt and chest belt to ensure she does not slip out of the chair. Case H is not frightened to use this technology. K8H also feels the Case H finds the bath more enjoyable than showers:

K8H: The bath tends to relax [Case H] because it is a more familiar thing than showers a comforting thing

Case H has swollen legs and has been assessed as At Risk of pressure sores. Staff cream her skin regularly to keep it hydrated and to prevent her from scratching.

Care home: grooming

Case H sees the hairdresser weekly but requires assistance on other days to comb her hair. Similarly she sees a podiatrist who takes care of her feet and toenails and requires assistance from staff to take care of her fingernails. Although she has loose teeth and sore gums Case H refused extractions and dentures from the dentist. Staff assist her with oral-care which she sometimes refuses.

Care home: dressing

Case H is always asked by staff what she would like to wear, to preserve her dignity:

K8H: We get her clothes out and just "Would you like to wear this today" or "Would you like to wear the red one today" sometimes she'll just ignore you but sometimes she'll nod or smile at you and so you go for that so she still gets asked

She receives total support to get dressed as she can no longer understand how to put on clothes appropriately or operate fastenings such as zips, buttons or shoelaces. Despite a previous shoulder injury she can move her arms and legs as the carers ask her to, or keep her arms where the staff have moved them to until they have finished dressing her. She typically wears loose stretch trousers to make toileting easier. She also wears hip protectors in case of falls. She may sometimes refuse to change her nightwear. Case H now has problems detecting her body temperature needs and acting on these; staff therefore should monitor her closely for this.

Care home: elimination

Case H is doubly incontinent and uses continence pads day and night. She is hoisted onto a commode or toilet at regular intervals to prevent the pads being used. She can sometimes detect her need to evacuate and will tell H1 or formal carers but may not always provide them enough time to get her to the appropriate location:

H1: She will very often say "I need to" and by the time we've got her there she's obviously had an accident

Case H cannot perform toileting activities such as wiping herself, flushing or washing her hands. H1 or staff must fully assist with these tasks. In the care home staff use antibacterial wipes to 'wash' residents hands:

K8H: [We] do it that way because getting to the sink and putting her hand under the water I think that can be a bit of a shock

Care home: eating

Case H is of a healthy weight. She has some physical difficulty when eating so has a plate guard to help her push food onto her fork. She sometimes spills food on herself when using cutlery, but the care home does not own angled forks or sporks which may prevent this. She can be slow when eating so sometimes carers feed her to ensure that the food she has is still hot. Carers also feed her when she is unmotivated or too sleepy to eat:

H1: I think now she's got to the stage where she just can't be bothered anymore

K8H: On good days she can still manage to feed herself but it's getting more days now that someone needs to help well we'll put it down in front of her and just see how she goes sometimes you'll have to go back and help her feed

She has damaged teeth and gums that give her pain. She therefore requires a soft diet or pureed food. She also has thickened drinks to prevent her from choking on fluids of normal consistency. She can usually hold a normal cup and saucer although has spilled drinks when sleepy.

Care home: family visits

Case H's main visitors are her son and biological daughter, H1. On good days they take her out of Care home #3 on day trips although H1 is less confident taking her mother out because of her impaired mobility, despite the use of the wheelchair. H1 will take her mother to the toilet when she asks but rarely do the siblings need to conduct ADLs with her. Visits are related to social activities and keeping their mother company.

Care home: end of life plan

A DNR Form has not been completed although there was a note in her care record to discuss this with the family and GP. Case H has been assessed as unable to make her own arrangements regarding the end of her life.

Case I Stage Two case study

Case I is a female in her mid-80s. She has AD, which was diagnosed 11 years ago.

Cognition

Case I was diagnosed with AD while living at home. Her GP and social worker referred Case I to a memory clinic after she presented to them with substantial memory loss. The consultant visited Case I at her home as she was unable to leave her husband, who she cared for.

Case I's cognition has reduced in the past two years. She was unable to complete her last MMSE due to her poor communication and ability to understand others. She can no longer attract attention to her needs and only rarely makes eye contact with others. This can make providing caring activities very difficult for the care home staff:

K9I: It's hard because you get used to getting feedback and you knew if they were happy or they were sad [but now] you don't really know because there is no communication

Family history

Case I and her husband did not have children. Her living family members are her nephew, his wife, I1, and their daughter. Case I and her nephew, I2, have a close relationship as his parents were away in the army frequently when he was growing up

Community life

Case I looked after her husband for approximately 12 years as he had heart problems and severe mobility difficulties. This was an extremely stressful time in Case I's life. They remained living in their home and would not consider moving to a smaller or more manageable property. After her husband's death, her social worker suggested moving to sheltered housing flats:

I1: He had discussed with her but she didn't want to she was adamant that she wanted to stay in her own home... she was considered to have sufficient capacity to make that decision

At home: medical and sensory conditions

In addition to her AD, while living in the community Case I had heart problems, hypertension, Parkinson's Disease, gout and epilepsy. She started to experience hearing difficulties. After her husband's death she was treated for depression by her local community mental health team.

At home: orientation

During her visits to Case I at home, I1 observed signs of disorientation and confusion:

I1: When I used to go and say "Hello [Case I]" she would always be in the lounge I'd go and make a cup of tea and when I would go back in she wouldn't even remember I'd already arrived it was like I'd only just walked in the room

Case I could no longer recognise herself and I2 had to move the hallway mirror upstairs as Case I was frightened by the 'strange old lady' who lived in her house. Her cognitive impairment also displayed through hallucinations and delusions:

I1: When we used to phone up er she would say "I've got some people here for tea at the moment" and she would set the table up for two [but] there weren't any people

Case I rarely left her house at this time so her social worker assessed that there was no risk of getting lost and therefore that she could remain living at home.

At home: mobility

Case I experienced increased mobility difficulties over the time she was caring for her husband. Her social worker requested I1 and I2 to move her bedroom furniture downstairs for two reasons: she began to have trouble negotiating her stairs and as her husband had to sleep downstairs Case I would sit in a chair all night to be near him in case he needed her. When I1 and I2 moved her bedroom downstairs, they discovered the first signs of her memory loss:

I1: There were thousands of notes she was writing absolutely everything down hundreds and hundreds and hundreds of bits of paper with every possible thing

I1 believes Case I's difficulties with stairs to be due to both cognitive and physical impairments. Physically, Case I was on her feet a lot of the time, had cellulitis and oedema in her legs and a long-term heart condition. Cognitively, Case I could no longer understand or perceive how to go down the stairs appropriately. Case I's husband had previously installed a stair-lift to cope with his immobility but he never used the device and instead lived completely on the bottom floor of the house. When Case I later had problems with the stairs, she did not remember how to use the stair-lift nor that she may use it as she perceived the item to be her husband's property:

I1: However many times you would tell her she just couldn't learn to use it basically so in the end we actually had it taken out so that the ordinary banister could be reinstated because then that would be safer for her

Due to her husband's immobility, their social worker arranged for the house to be equipped with grab-rails throughout. Case I was also fitted with a telecare pendant alarm system but she could not remember how to use the alarm or to wear the pendant:

I1: It would be days before the [carers] could even find it and whether she would have ever actually used it is a bit debatable because although it had been explained to her what it was for I'm not sure she would have retained that information sufficiently to use it

At home: washing

The social worker also assessed that Case I could benefit from a downstairs bathroom. Case I was a little reluctant about the change if it meant spending money, but the social worker helped her to apply for a DFG. The application was still being processed when Case I relocated to Care home #3. However I1 perceives that had a downstairs bathroom been installed, Case I would have rarely used it as she would have automatically left her lounge and gone upstairs:

I1: We'd all discussed that when the social worker bought it up and said we'd probably have to gate off the bottom of the stairs so that she could not go upstairs

Prior to relocation, Case I was not able to bathe alone as she was too physically impaired to get into and out of the bath safely. Formal carers helped her to bathe using a transfer aid.

At home: grooming

Case I could perform grooming activities adequately while living at home.

At home: dressing

Case I experienced substantial limitations when dressing. Her visuo-spatial impairment meant that she had difficulty getting into her clothes appropriately.

At home: elimination

Case I had a commode downstairs that her husband had previously used. Although her mobility difficulties progressed considerably and she could not reach the bathroom easily, she rarely remembered to use the commode. Furthermore, when confused she could not use any toilet facilities appropriately:

I1: She stayed with us for Christmas when her husband had died two days before.... she used the bathroom [and] there was faeces absolutely everywhere

I1 perceives that such incidents were either because Case I could no longer understand how to wipe herself after evacuation, or her visuo-spatial impairments meant that she could not perform the task adequately. She did not have incontinence problems.

At home: eating

Case I could eat well when she lived at home.

At home: informal and formal carer assistance

I1 and I2 lived some distance from Case I's home, so telephoned frequently and visited twice per month. They ordered a food delivery online for her weekly. Case I's husband had always managed the household finances but could no longer leave the house to get to the bank. Case I had rarely handled such matters in her life and was becoming too cognitively impaired to take over these tasks. I2, as Case I's nephew, helped manage their finances and organise other household matters. I1 and I2 have LPA for Case I.

As a petite person she found looking after her tall husband difficult so he had regular formal carers to attend to his hygiene needs. The same carers over time also provided services to Case I. They assisted her with domiciliary tasks and with bathing, dressing and toileting. After her husband died the formal carers visits increased to four times per day. Over time she forgot to prepare food and wouldn't use the ready meals I1 bought for her. There were also problems with the meals-on-wheels service:

I1: The people would come in put the meal on the table and the minute they walked out of the door [Case I] wouldn't remember they'd been there so she would discover the meal later on wouldn't really understand what it was and where it had come from

Her depression also affected her motivation to eat. Case I's formal carers then took over this ADL and ensured that she ate. She could use cutlery well. She was also put on liquid nutritional supplements to compensate for a previous malnutrition. The formal carers also ensured that she took medication appropriately.

Relocation

Case I relocated to Care home #3 in 2005. The decision was triggered after Case I fell during the night. She was found by her formal carers in the morning:

I1: [Case I] herself was not able to communicate any information about anything because her short-term memory was such that she didn't know why she was there what had happened

Case I was a hospital in-patient for approximately eight weeks. While there, her cellulitis worsened because she rarely moved and the hospital did not give her the tablets she regularly took for this. I1 and I2 found communication with the hospital staff extremely difficult throughout this time and their understanding of a patient with AD to be poor:

I1: They seemed to be pretty vague about what it was that she was there for only that she was a bit of a nuisance really because she was quite disoriented... I mean she was always disoriented but even more so being in hospital... they had written in her notes 'no staff time to feed'... they've come round they've put the meals on the table they'll collect the uneaten meals and they go

On the planned day of discharge I1 received a call from the hospital staff; they needed to keep her in as they had discovered Case I had a chest infection. During the inpatient stay she also saw an old-age psychiatrist who scored her 12 on the MMSE. This was markedly lower than the recent MMSE scores that Case I had during her regular visits to the memory clinic; Case I is certain that the hospital stay contributed to an accelerated cognitive decline. The psychiatrist's report recommended for Case I to be relocated to a care home that could take people with dementia. This was not discussed with I1 and I2:

I1: The only consultation we got was from the Discharge Co-ordinator who said "Right [Case I]'s got to go to a nursing home I'll send you through a list"... I don't think we realised that actually we had the choice and we could probably say "Actually you know what we think she can be managed at home if she had a full-time [carer] that's what we're going to do" but at the time we were less au fait with the system than we are now

Although I1 and I2 did consider appealing the decision, they saw that Case I was declining very quickly in hospital. They preferred to remove Case I from the situation as quickly as possible rather than wait further time for a home assessment to see if Case I could remain living at home. I1 and her husband were pressured to find a suitable care home for Case I as quickly as possible. The list of care homes they were provided included only two suitable locations, one of which was Care home #3.

I1 and I2 initially hoped that the relocation would only be for three months for rehabilitation and respite and that Case I could return to her home with a live-in carer, in line with her expressed wishes. However Case I's condition declined further; she was extremely disoriented and stopped eating and drinking:

I1: They got a psychiatrist in to do her mental health assessment to see whether she should be force-fed or something like that but with a bit of tender loving care they did get her back eating

I1 and I2 were also unable to get an appropriate professional to assess Case I's ability to return home. The window of opportunity to move Case I back home had passed. By six months post-institutionalisation, Case I was settled at Care home #3.

Care home life

Case I is now bed-bound. She does not leave her bed or bedroom at all and cannot participate in social activities. She is unresponsive to others. Carers put classical music on her radio for company and in the hope that she can perceive it:

K9I: But then sometimes you think well what if she's sick to death of that now what if she doesn't want music on or what if she would like another radio station or little things like that it's hard to know what you're doing is right for her

The staff sometime show Case I her photograph of her and her husband but she does not communicate that she recognises or sees it:

K9I: You don't know whether you're doing more harm than good sometimes perhaps she would like to look at a photo of her and her husband or perhaps it's quite distressing or perhaps there is no recollection of who that man is

Staff use lemon swabs to moisten her mouth and keep her comfortable. She has a disturbed sleep pattern and may be confused on waking. At night she is repositioned frequently.

Care home: medical and sensory conditions

Case I is prone to UTIs. Carers must check whether Case I has had a recent bowel movement before providing anti-constipation medication. She suffered a femur fracture after a fall in the care home. In November 2011 she had a large gastric bleed for which she was admitted to hospital and had a blood transfusion:

I1: They said they thought she'd got bowel cancer they weren't going to do any investigation to confirm that because it was quite an invasive procedure and in any case it wouldn't alter their treatment plan which was that she should only be having palliative care... they made it very clear that they wouldn't be [providing healthcare] again

Case I was returned to Care home #3 on a palliative care plan, which she has been on for almost two years:

I1: Obviously that isn't what's happened and she's still here whether she's got bowel cancer or not [laughs] I've no idea

Initially the staff tried to sit Case I up in her chair but she would slip and slump; she now remains in bed.

Care home: orientation

Case I now has severe disorientation but does not leave her bed so is not at risk of getting lost. She does not indicate that she recognises anybody or anything:

K9I: Her focus is just somewhere else... you could be sitting there feeding and talking and then you'll make her jump because she's not aware sometimes that you're still there

Case I does not appear distressed by her disorientation. I1 perceives that Case I may startle if she hears a sudden loud noise but does not register familiar noises such as the vacuum cleaner.

Care home: mobility

Due to her femur fracture and subsequent immobility, Case I is now bed-bound. She cannot sit up as she cannot balance or hold her body up appropriately. She can move her arms a little and sometimes may be able to hold another person's hand. When she was more mobile, carers used the stand-aid hoist with appropriate sling to sit her on a recliner in the lounge or into a wheelchair. Now the stand-aid hoist is only used to weigh her. She has little fat on her body and bruises easily; to

prevent harm when moving two carers use a slide-sheet to reposition her every two hours. She has no pain when at rest but slight pain on movement.

Case I's bed has wheels and can be tilted to prop up her head or legs. She has cushioned bed-rails in place in her bed because although immobile she suffers from seizures and could fall. She is not disturbed by the bed-rails. There is soft cushioning on floor but no alarmed pressure mat. Her mattress is air-cushioned to prevent pressure sores; it makes a noise but does not bother her.

Care home: washing

Two staff provide bed baths to Case I, repositioning her with a slide-sheet as necessary. A flannel is used for her face and limbs and disposable wipes for her genitals. These wipes are not wet wipes but 'dry wipes' that soap up when rubbed.

In addition to her pressure mattress, staff lotion her skin with aqueous cream and lavender oil after washing. They particularly focus on known areas at risk of pressure sores such as her sacrum and heels. They then place blue pressure-booties on her feet.

Care home: grooming

Case I's hair is cut every three-six months. She requires full assistance with nail-care and a podiatrist visits every three months to cut her toenails. She does not wear make-up. Carers manage her oral-care. They also put deodorant on Case I.

Care home: dressing

Case I now only wears night dresses and pressure-booties. She is dressed by the staff and she cannot assist them by moving her legs or arms. Staff always tell her what they are about to do to preserve her dignity. Case I cannot choose what to wear. She has no awareness of body temperature and because of her frailty is vulnerable to changes in the weather.

Care home: elimination

Case I is doubly-incontinent. She must be offered lots of fluids to prevent UTIs and constipation. At one time she had a catheter which was to remain in situ until a pressure sore on her sacrum healed. Usually she wears continence pads with net knickers as she cannot sit on a toilet or commode. Her pad is checked every two hours when carers reposition her. At night she also lies on a disposable sheet that prevents urine from soaking into her bed clothes, so protecting soreness from wet fabric.

Care home: eating

Case I's BMI indicates that she is underweight, so she continues to take a nutritional supplement. Full feeding support is given with meals; she is propped up in bed and staff give her pureed food on a spoon. This is because she forgets to chew properly and to swallow. The care record stated that her drinks are modified with Grade 1 thickener but K9I claims that she still has drinks of normal consistency; cups are held to her mouth by staff and she sucks through a spouted lid.

Care home: family visits

I1 and I2 visit Case I every two to three weeks for 20 to 30 minutes. Due to her immobility they cannot take Case I out of the care home. They do not conduct intimate activities for or with Case I:

I1: The last time I came the two ladies came to change her continence pad I went out of the room to give [Case I] some privacy it seems a bit stupid really because she's totally unaware anyway it's a matter of courtesy and dignity

They also try to avoid visiting during mealtimes, However K9I indicated that if they do visit Case I during a mealtime the staff simply return later with her food. Similarly, if staff need to reposition Case I they try to wait until after her visitors leave to prevent disturbing their time together.

Care home: end of life plan

Case I is on a palliative care plan. A DNR Form was completed in September 2012 as heart massage would cause broken ribs. Case I has been assessed as unable to make her own arrangements regarding the end of her life.

Case J Stage Two case study

Case J is a female in her early 90s. She has VaD which was diagnosed six years ago, possibly as the result of a stroke.

Cognition

Case J's capacity to make decisions fluctuates as she struggles to retain and understand information in order to make significant decisions. She had poor scores in relation to recall and orientation on her last MMSE. In the past she was aware of her poor memory and cognitive impairment:

J1: She would say "I feel like I'm losing my mind" so there was an element of knowing the damage that she was sliding into something she didn't understand and that was sad because I didn't expect her to be that cognitively aware even eight months after the stroke

Her cognitive and physical impairment also mean that she cannot walk away from danger. However she does hit back when hurt or feels threatened and indeed has a history of becoming agitated and both verbally and physically abusive.

Family history

Case J married her husband in the 1950s. She has three biological daughters and three step-children. The family lived in multiple countries throughout the 1950s-1980s. Case J was widowed in the 1980s.

Community life

After her husband's death Case J lived alone in a different part of England to her daughters in a third-floor flat. This flat was close to her step-son. As she became less physically-able Case J moved country to be closer to her daughters' shared house, at their suggestion. She chose a first-floor flat as it felt safer to her than a ground-floor flat. She was a strong-willed lady and would not have enjoyed living with others. She was very independent but had some help from her children with DIY activities. However she was safety-conscious and stopped leaving her residence once night had fallen because a neighbour had been attacked.

In 2004 she went to hospital for a brain scan after she frequently passed out and fell. She was unhappy when her daughters suggested she stop driving but was able to take buses to the supermarket or other appointments. Case J loved television and radio and writing letters.

At home: medical and sensory conditions

Over time Case J began to suffer ill-health with chest problems and an arrhythmic heart. She was fanatic about taking her medication and recorded her intake in a book.

Case J had many falls including a major injury after a fall up her stairs which resulted in surgery on her leg. Case J had multiple TIAs while living at home and then had a full stroke. This led to a protracted in-patient hospital stay. After her stroke she showed more symptoms of dementia additional to her poor balance:

J2: It would take the big major stroke for the prognosis to come in then to be able to turn round and say "Oh with retrospect possibly that fall up the stairs" [was a sign of dementia]

Her poor memory became more apparent to J1 and J2, and she began to be 'sharper' in her verbal communication; J1 feels that she was covering up or embarrassed about her reduced cognition.

At home: orientation

Case J was not disoriented to date, time or place while living at home. She began to forget her daughters during her long stay in hospital, as is discussed further in the 'Relocation' section.

At home: mobility

Case J began to be very imbalanced when walking. She fell frequently so her daughters purchased a pretty-patterned walking stick for her. She used this AT after J1 persuaded her that the stick was for others' benefit rather than her own:

J1: She didn't want to be seen to need help... I said "You need to use the walking stick for the likes of me who are walking down the street [and] quite quickly will get annoyed you're not moving but if I saw a walking stick it gives me a heads-up this person's unsteady on her feet they're not gonna go very fast" I said "It's not about you mum" so of course she thought ok then I'll use my walking stick

At home: washing

Due to her reduced balance Case J stopped using her bath and only had showers. Her daughters purchased a bath lift, which consisted of a sling that stretched across the bath and lowered the user into and out of the water. J1 and J2 believe that Case J did not use the device:

J1: I don't think it was sturdy enough for her or she didn't feel confident using it

Generally, Case J was reluctant to accept any assistance if she felt that others had to go out of their way to help her. She refused for them to try a different type of bath lift. Instead her daughters purchased non-slip bath stickers as an alternative to a bath mat to prevent Case J from losing her footing when showering:

J2: Once she'd decided she didn't want it and want to use it you were not going to convince her to use it so [we said] "Well fine don't use the bath we'll sort out the shower footing"

At home: grooming

While living at home Case J was able to perform grooming ADLs.

At home: dressing

Similarly, Case J was able to dress herself appropriately.

At home: elimination

Case J was able to detect her need to evacuate and could reach her toilet on time.

At home: eating

Case J could take care of her food preparation and eating needs. She had standard crockery and cutlery. She liked kitchen gadgets:

J1: She was very much a gadget woman because dad was an engineer... she liked efficiency so she didn't have a problem with gadgets like new type of mops or cleaning stuff or anything that would make your life easier

She used an AT to make opening jars easier. She could use a microwave and oven appropriately.

At home: informal and formal carer assistance

Case J did not require her daughters to conduct any ADLs with or for her. They instead provided practical help, for example when her microwave or washing machine was broken they helped her to fix it or buy a new product:

J1: We used to find her plumbers and electricians so that we could trust them

J2: But we would still leave her to ring that plumber up

Indeed, the day Case J had her stroke J2 found her on the floor because she was visiting to help Case J arrange a new television rental and Case J had not answered her telephone.

Relocation

Case J was admitted to hospital after her stroke. Her dementia symptoms increased and worsened during her time there. During her time on the rehabilitation ward, the healthcare staff perceived that Case J would not be able to manage in her home alone due to her confusion; Case J was not aware of her physical state or how much weight she had lost. She could not perceive that she was being tube-fed to help nourish her body and would pull it out frequently. She could not recognise her visitors. When considering whether Case J could live at home with a care package, the main concerns were her risk of falls and ability to wash and feed herself. Her daughters perceived that Case J would be reactant and verbally or physically aggressive to formal carers and other services such as meals-on-wheels. They discussed the possibility of taking it in turns to live with her to provide caring assistance but this was agreed to be unfeasible:

J1: They said there was nothing more they could medically do for her they said "Can you take her home" we went "No" because there was no room in our house plus our house is too dangerous for her... then the psycho-geriatrician said "She's got VaD you need to find a home for her"

The sisters then searched for a care home that could take Case J. The home they selected was qualified to take people with dementia but could not cope with Case J:

J1: They were atrocious she was aggressive they didn't know how to deal with her she lost a stone in a month and then that really freaked them out... we started buying [nutritional supplements] but they were all left in the fridge they weren't giving them her... we would go in and say "How's she doing" and they would say "She's done this she's done that" like it was our fault she was badly behaved

J2: She wouldn't sit in the u-shaped circle and stare into space

Not only was Case J malnourished but she continued to experience falls and injuries, which the care home were not recording. After three months she was aggressive towards another resident who fell and broke their hip. Case J was taken to a mental health hospital by the care home staff after she would not settle one evening and walked along the corridors banging other residents' doors:

J2: She'd actually gone in at eight-o'clock but they didn't bother to tell us until eleven-o'clock that night

Case J became severely disoriented and delusional during her four month stay in the mental health hospital. She was prescribed anti-psychotic medication. Her care home refused to accept her placement back with them. Her assigned CPN recommended Care home #3. She moved there in 2008.

Care home life

Currently, Case J is an active member of the social community in Care home #3. She can walk and talk to other residents on 'good' days. She is strong-minded and will not do anything she does not want to, for example some days she wants to stay in bed:

K10J: We try and encourage her to get out and say things like "Your bed needs changing" or "Come out and have your breakfast if you want to go back after I'll leave the bed open and you can come back"

Although the philosophy of Care home #3 is very much one of preserving dignity and choice, staff do try to persuade Case J to get up if she has been in bed for more than two consecutive days. They feel it would be unwise for her physical health, cognitive health and social well-being if Case J stayed in bed every day, particularly as on those days Case J is more reluctant to eat and drink:

K10J: You know it's not good... if she's not drinking that's where the UTIs come into it so you're just going round in a vicious circle

At times Case J thinks that she lives in a previous home from her youth. She is still sometimes physically aggressive and hits others with her walking stick. As a result of such aggressive behaviour staff are instructed to continue with orientation therapy, de-escalation techniques and one-to-one time to allow her to verbalise any concerns she may have.

Case J is generally independent with night care activities although may require some prompting to get ready for bed. Occasionally her sleep pattern is disturbed and she has been heard talking to herself at night.

Care home: medical and sensory conditions

In addition to her VaD, Case J now suffers from TIAs, hypertension, atrial fibrillation, COPD, hyperlipidaemia, seizures and arthritis. She is not suitable for Warfarin because of her dementia and high risk of falls. She is an ex-smoker and uses inhalers to combat her breathlessness. She takes anti-depressants.

In September 2011 she made reference to hearing voices commenting on her activities so took an antipsychotic for a while. The GP was also considering medication for low mood and appetite. She is susceptible to UTIs which can cause delirium. She has been known to refuse medication, or refuse her morning pills but take her night ones.

She now has macular degeneration and wears spectacles. Her daughters purchased from her optician a magnifying glass on a chain to go around her neck. She does not use this AT. She also has a hand-held magnifying glass with lights, but does not use this AT either. She forgets they are there for her use:

J1: She doesn't remember which drawer it might be in and then if she does remember she hides it

J1 also perceives that the chained magnifying glass required too many adjustments for Case J to manage.

Care home: orientation

Case J is able to find the bathroom if she needs it, but is unlikely to find her room on her own. Disorientation makes her anxious. She sometimes asks when she is leaving Care home #3 if she hasn't remembered she lives there. She recently managed to leave the care home alone through an open side door while maintenance staff were working. She was found in the car park. When this was discussed with J1 and J2, they felt that Case J would not have been able to find her way back to Care home #3 had she walked further.

Care home: mobility

Case J can walk with a stick or a walking frame with wheels. Sometimes she forgets where she put her stick, which is the same pretty one she had when living at home. She also uses furniture to maintain balance. Staff must supervise her when walking as her balance is poor and she is at risk of falls; she was regularly found on the floor because she can lose consciousness and fall heavily. J1 indicated that Case J likes having a person on either side of her when she walks. Staff know that when she seems vacant this is a clue that she might lose consciousness and fall. She requires physical assistance for transferring but does not use a stand-aid hoist. Her daughters have borrowed wheelchairs from the care home when she goes to hospital appointments.

There is a pressure mat sensor next to her bed at night as she does get up to use the toilet. She does not require bed-rails as she can climb in and out of bed, although at times needs assistance. Furthermore she will be resistive and angry if bed-rails are in place. Staff must ensure that her bed is set to the lowest level.

Care home: washing

Case J requires the assistance from one carer to manage her personal hygiene needs. Although previously Case J could wash her upper extremities with verbal prompting, now staff provide full physical assistance to wash. K10J indicated that she may sometimes pick up a towel and pat herself dry but usually does not understand what is happening. She enjoys regular baths but sometimes refuses to wash. She requires significant intervention by staff with skin care as her skin is thin and dry.

Care home: grooming

Case J likes her hair washed prior to being set by the care home hairdresser. She is able to brush her teeth with supervision. She is regularly visited by a podiatrist for foot care, and the care home staff trim her fingernails.

Care home: dressing

Case J requires support to be as independent as possible when dressing and can make simple choices between clothes. She wears hip-protectors in case of falls; these were purchased by the care home. However they impact her ability to go to the toilet alone as they are bulky and difficult to remove. She sometimes refuses to wear the hip-protectors. Staff must also ensure she wears well-fitting footwear to prevent falls. Case J is now usually dressed completely by the carers, however J1 found it hard to determine whether Case J could perform some dressing tasks herself:

J1: I think it's hard to tell because I think she likes being waited on sometimes

She can no longer put on 'fiddly' items and stockings, as her co-ordination has decreased. As Case J got older, her daughters persuaded her to change the style of clothes she was wearing to items with elasticated waists, fewer zips and buttons. Case J also used to make her own culottes and made the waists elasticated; she still recognises these items when asked what she would like to wear and can advise the staff which side the pockets should go.

She can generally express her body temperature needs although may require some prompting. That is, staff may need to directly ask her whether she is too warm or cold. They also need to operate the windows in the lounge and her bedroom.

Care home: elimination

Case J can be incontinent of urine and faeces. Staff regularly prompt her to use the toilet and she can usually detect her need to evacuate. However she finds it difficult to get to the toilet because of mobility so wears incontinence pads in case of accidents. These pads are checked every two hours by staff. She has a commode next to her bed at night. She is prone to constipation for which she has laxatives and massages when needed. Due to her increased susceptibility to UTIs, staff regularly monitor her urine for infections:

K10J: If she's had a day where she's stayed in bed [or] a little bit grumpy we just dip in the sticks and see what's in her urine

Care home: eating

When in hospital Case J would refuse to eat, and has been reluctant to eat since then:

J1: She didn't wanna eat and the doctor said "[Case J] you're like a car you've gotta put fuel in to run therefore you've got to eat to make you run" and that I think helped her but she was fighting eating then

She usually feels that eating is too much of an effort for her. Due to swallowing impairment as an effect of her stroke, Case J now eats a soft diet. She needs encouragement and prompting, but not always physical support to eat. The amount of assistance she requires is related to 'good' and 'bad' days. She has a daily nutritional drink to prevent malnutrition. Staff must ensure she drinks plenty of fluids in hot weather as she cannot detect if she is thirsty. She can however hold a cup and saucer if placed in her hand. Mugs are too heavy for her. Her drinks are usually thickened.

Care home: family visits

Case J's daughters take their mother out of Care home #3 on hospital appointments. They usually try to have at least two of the three daughters with her at these times. They usually borrow a wheelchair from the care home to help Case J's mobility. J1 has maintained a disabled parking certificate so that the daughters can access convenient parking when out with their mother. The daughters have helped Case J to dress and to groom herself, especially on days she hasn't been ready when they need to get to an appointment. However they do not perform washing or bathing activities with their mother. They do not take Case J into the toilet, although assist her there if necessary, and usually find a carer to help her when she needs to evacuate:

J1: It's one step too far for me if I had to I would

J2: I've helped her once... because I don't think there was anyone round at the time she was quite capable of doing everything herself just pulling [down] the hip protectors

Case J's daughters do help to feed their mother if they visit during mealtimes. They assist her with drinks and snacks throughout their visits.

Care home: end of life plan

A DNR Form was completed in September 2012. This was because it was thought that Case J would not survive CPR. She has been assessed as requiring support in making arrangements regarding the end of her life.

Appendix 7: Thematic analysis

Initial themes resulting from first level of thematic analysis

Theme titles (alphabetical)	Description of the theme, sub-themes if appropriate, and example quote
ADL performance while at home	Any issue with the ADLs or mobility while at home, specifically for performance of an activity (more detailed than, e.g. <i>'she was getting confused'</i> which would go in the Dementia and Co-morbidities theme): <i>'She was leaving the taps on all the while'</i>
ADL performance, life and help in the care home	Issues with ADLs, mobility, care received for these and for general daily life whilst in the care home: <i>'She now makes herself cups of tea which she hadn't done for a long time'</i>
Appropriate community housing environments	Anything related to whether the person moved to a more suitable environment (e.g. a ground floor flat) or had environmental adaptations because of their abilities or the abilities of a previous tenant: <i>'The bathroom was changed because of my husband's stroke'</i>
Assistive Technologies in the care home	Any notes on ATs or environmental adaptations that the person uses now they reside in a care home (even if they use them outside e.g. one son keeps a lightweight wheelchair in his car for day trips but he only bought that since his mother was in a care home): <i>'We do have problems with her cleaning her teeth but we've put signs up'</i>
Assistive Technologies at home	Any ATs used by the person in their home (distinct to environmental adaptations): <i>'She'd got a pendant that used to hang beautifully on her rocking chair'</i>
Benefits of knowing life history can help personalised and appropriate caring	Keyworkers' acknowledgement of the usefulness of the life history in the care record or their knowledge of the person before they became uncommunicative, e.g. to help them interpret behaviour: <i>'She can get upset in the afternoons between three and five... it's related to thinking it's time to go home from work'</i>
Choosing the right care home	How people heard about which homes to visit, their thoughts when visiting including what they did and didn't like, whether formal services helped with a list or refused to assist (although straddles the service theme also), and also how choice was determined by externals e.g. the person with dementia themselves or the care home eligibility criteria, whether ADL needs were taken into account: <i>'It had more of a hotel feel to it than a care home feel it hadn't got a smell'</i>
Dementia and co-morbidities	Anything related to dementia symptoms and cognitive issues including mood and any other conditions or diseases: <i>'She had the stroke eight years ago and it became immediately apparent that there'd been brain damage of some kind'</i>

Theme titles (alphabetical)	Description of the theme, sub-themes if appropriate, and example quote
Diagnosis of dementia	Anything related to how and when a diagnosis was made: <i>'Referred her to the mental health team and they came straight out and said she'd got VaD'</i>
Everyone's different and stories	Quotes that relate to the individuality of the residents and how they and their experiences differ: <i>'It will also depend on each individual be totally different they're all completely different with what they can and can't do and will and won't do'</i> Plus stories that do not fit into a theme but are possibly relevant, or outliers, e.g. one resident was taken out of the care home to go on a cruise and that's where the daughter truly realised how bad the dementia was as the mother couldn't understand why scenery changed, or get dressed
Family visits in the care home	The nature of informal carer's visits to the people with dementia now they reside in the care home including any specific care for ADLs: <i>'I will do her nails for her because she likes having that done'</i>
Formal carer training	The dementia-specific training carers had and any benefits they perceived it to have: <i>'We had to bring six items that are really close to us in and then imagine if we'd lost them... how you know somebody with dementia might have felt that they've lost something like their home'</i>
Informal carer activities, coping strategies and emotions	The care and support that informal carers gave to the people with dementia while they were living in the community: <i>'I did all the shopping and stuff'</i> Any notes about the way that they do things to cope (e.g. with cognitive or physical issues): <i>'I told her after about two months of being here her flat had been knocked down'</i> Anything related to the way that informal carers felt about something (emotive language): <i>'You need to look at her going into a home you know and so I was absolutely mortified'</i>
Obtaining ATs at home	Where and how people obtained the ATs or environmental modifications that we used in the community setting: <i>'The physiotherapist told me what we needed and she measured what we needed'</i>
Potential use of other technologies	When interviewees considered the use of other technologies with the resident: <i>'[Discussing a voice-prompted smart technology for hand-washing] I don't think he would understand it'</i>
People with dementias' voice	The person's voice on these issues, how they felt about, e.g. relocation, living in a care home, the use of ATs: <i>'She was absolutely livid putting it mildly "Well go away then now I don't want anything to do with you ever again how could you do this to me" and I felt awful'</i>
Reasons for not living together	The justifications that informal carers provided for not having

Theme titles (alphabetical)	Description of the theme, sub-themes if appropriate, and example quote
	<p>their parent live with them in their home: <i>'If she'd have been with me I'd have been at work all day and she would have been bored and isolated'</i></p>
Relationships with social and health services and receiving formal care in the community	<p>Any contact or communication between the caring dyad and any formal health or social services on any matter, whether contact was positive or negative and their experiences with these: <i>'I had lots and lots of battles not with mum but with other people'</i></p> <p>Any formal caring service that was entering the person's house to provide caring: <i>'He needed two or three at a time... the problem was the didn't turn up at the same time'</i></p>
Relocation or the decision about it	<p>How the decision was made, who made it, why it was made: <i>'They said your mum's definitely not well she's not herself I think you need to look at her going into a home'</i></p> <p>The experiences of relocation and what happened: <i>'We took stuff from her flat so it looked as much like her home as possible'</i></p>

Potential themes resulting from second level of thematic analysis

Theme	Sub-themes and example quote or care record information
Theme 1: Cognitive and physical functioning in the community	<p>Dementia signs: <i>'You'd be sitting talking to her and she'd suddenly sort of go "I'm going away"'</i></p> <p>Dementia diagnosis: <i>'They did the test... that's when they said "Oh it's vascular dementia"'</i></p> <p>Co-morbidities: <i>'In addition to her VaD, Case J suffers from TIAs, full strokes, hypertension, atrial fibrillation, COPD, hyperlipidaemia, seizures and arthritis'</i></p> <p>ADL performance while at home (separated by ADL): <i>'I mean the dressing thing she would couldn't work out how to get her body parts into [laughs] the right bits of the clothes'</i></p> <p>Informal carer activities: <i>'I felt a huge responsibility she is my mum I needed to do it I needed to look after her'</i></p>
Theme 2: Assistive Technologies used at home and housing environment	<p>Assistive Technologies at home (separated by ADL): <i>'We got it [bath lift] for her and put it in I don't think she hardly used it I don't think it was sturdy enough for her'</i></p> <p>Type of housing: <i>'She lived in a ground floor flat on her own which was classed as semi-sheltered... it had live line panic alarms and a travelling warden who went in about once a week'</i></p>
Theme 3: Perceptions of ATs and relationships with formal services	<p>Perceptions – preferences and barriers: <i>'There's only so much you could do because then she say it was too much fuss'</i></p> <p>Potential use of other ATs at home: <i>'Glass-fronted cupboards would have been great'</i></p> <p>Obtaining Assistive Technologies at home: <i>'We had one [walking stick]... I think my father made it'</i></p> <p>Relationships with formal care services: <i>'Once they started she didn't like the idea of it so she kept cancelling it'</i></p>
Theme 4: The relocation decision	<p>The tipping point for the relocation decision: <i>'Then she started running away from the flat'</i></p> <p>Professional involvement in the decision: <i>'That was when they said no you can't send her home she's got to have a [care] home'</i></p> <p>Difficulty making the decision: <i>'Isolated stressed anxious so so upset and guilty awful absolutely awful'</i></p> <p>Person with dementia's voice: <i>'Towards the end I don't think she really cared... she [was] obviously getting sick and tired of going in and out of hospital'</i></p> <p>Reasons for not living together: <i>'She [sister] said "Well perhaps she could come live with me" and I said "But you couldn't go out"'</i></p> <p>Choosing the right home: <i>'[The lack of smell] it's a small thing but a very important thing I think'</i></p> <p>The relocation experience:</p>

Theme	Sub-themes and example quote or care record information
	<i>'It was a bit traumatic on the day because she refused to get anything ready'</i>
Theme 5: Care home life	<p>ADL performance in the care home (separated by ADL): <i>'Food is now liquidised and drinks are thickened as she has swallowing issues related to reflux'</i></p> <p>Assistive Technologies in the care home (separated by ADL): <i>'She has a raised, winged toilet seat in her bathroom'</i></p> <p>Potential use of other ATs in the care home: <i>'[An angled fork] might help her yeah'</i></p> <p>Carers' dementia-specific training and the benefits of knowing life history: <i>'With the training you know it enables staff to understand a little bit more'</i></p> <p>Family visits to the care home: <i>'She actually eats better for her [daughter] than she does us [staff] some days'</i></p>